REGIONAL CONFERENCE ON MENTAL RETARDATION

March 11 - 13, 1958

HOTEL ST. CLAIR
Chicago

STATE OF ILLINOIS

WILLIAM G. STRATTON
Governor

OTTO L. BETTAG, M.D.
Director, Department of
Public Welfare

REGIONAL CONFERENCE ON MENTAL RETARDATION

presented by the

ILLINOIS DEPARTMENT OF PUBLIC WELFARE

in cooperation with the

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service

MARCH 11 THROUGH MARCH 13, 1958

at the

HOTEL ST. CLAIR

CHICAGO, ILLINOIS

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OPENING COMMENT

Mr. Willard L. Couch

Dr. Joseph E. Duty, Commissioner of Mental Hygiene in the State of Ohio, became suddenly ill and was taken to the hospital and Dr. Butcher, the Superintendent of the Columbus State School will take his place on the program.

I do not know how many of you have had time, after registering, to notice the exhibit of the medical center, which is out in the corridor beyond the registration desk. In the West Side Medical Center in Chicago, one of the outstanding medical centers in the country, the Illinois Department of Public Welfare is constructing the Illinois State Psychiatric Institute for research and training. We have funds and are in the process of planning for a pediatric hospital for mentally retarded children six years of age and under, which is to be constructed immediately adjacent to the Psychiatric Institute here.

Illinois has the advantage that the fifth region of the United States Department of Health, Education and Welfare is located here in Chicago. I do not infer that the staff of that organization is not giving the same services to Indiana, Michigan, Ohio and Wisconsin, as to Illinois, but at least they are a little more accessible to us. Being accessible to them, our staff and their staff has had the opportunity to get together on the program here that has been worked out in regard to mental retardation.

Actually Dr. James F. Maddux, Chief, Mental Health Service, Dr. Margery Mack, the Social Science Consultant, Miss Dorothea Dolan, Psychiatric Social Work Consultant, Miss Catherine Morgan, Mental Health Consultant in Nursing of the Fifth Regional Office of the Department of Health, Education and Welfare and Mr. Lawerence A. Bussard of the Mental Health Service of the Illinois Department of Public Welfare are primarily responsible for developing the program.

The program as you will see, is on a very informal basis. Our school teachers have said to us, "What we get out of it, is in proportion to what we put into it". I think that it is intended that we will all take a very active part in the program.

The Director of the Illinois Department of Public Welfare is in his fifth year in that capacity. During that period, the department has made very rapid strides in the mental health field, particularly in research, and professional training.

The legislature in Illinois passed the bill creating the Psychiatric Advisory Training and Research Authority which we hope will be a continuity and stimulation to research and professional training in Illinois. It was largely through the boost that was given to it by Dr. Bettag.

It is my privilege to present to you, Dr. Otto L. Bettag, the Director of the Illinois Department of Public Welfare.

WELCOME

Otto L. Bettag, M.D.

Thank you, Mr. Couch, you are welcome to Chicago. I have the privilege of reading two telegrams that were just received. One from Marion B. Folsom, Secretary, United States Department of Health, Education and Welfare, and the other from Governor Wm. G. Stratton of Illinois. The telegram from Mr. Folsom is as follows:

'On behalf of the United States Department of Health, Education and Welfare, kindly convey my warmest greetings and best wishes to the delegates for Region V conference on mental retardation. It is a privilege for this department to have the opportunity to act as a sponsor with its regional office and the Illinois Department of Public Welfare. This conference of five leading states should be a significant milestone in the developing of more effective services for the mentally retarded. Congratulations on a most worthwhile endeavor'.

The second telegram from Governor Stratton reads: 'Welcome to the nation's first regional conference on mental retardation. Illinois is proud to serve as host and as co-sponsor. I know of the aims and goals of the conference and heartily applaud your concern in this important field. May I wish you every encouragement for a productive meeting'.

In looking at the early history on mental retardation, we find that in most cultures, the retardates were objects of hatred. In fact, in Greek history, we find that they were taken as infants to the mountain wilderness and left there to die of hunger and exposure.

It has been only in recent years that the retarded child has become the concern of professional people, state and national governments.

As part of the interest and concern, this first regional conference on mental retardation is being jointly sponsored by the Illinois Department of Public Welfare and the United States Public Health Service of the Department of Health, Education and Welfare.

From the beginning, response to the idea of holding such a conference has indeed been most gratifying. We are pleased that so many of you have taken time from your busy schedules, and from your work with the mentally retarded persons under your care, to attend this conference.

We hope that through the exchange of ideas as to what Indiana, Ohio, Michigan, Wisconsin and Illinois are doing in the field of retardation, that as state administrators, institutional superintendents and other agency heads, we will all be able to take back ideas that will help us work more effectively with the problems which we now face, and to keep pace with the progress which is constantly going forth at national and state levels.

Again... welcome to Illinois. And let us hope that this first Regional Conference will be the forerunner of many such conferences devoted to the problem of mental retardation with which we are all so deeply and vitally concerned.

A NEW VIEW OF AN OLD PROBLEM

By
George S. Stevenson, M.D.
National and International Consultant
The National Association for Mental Health

On several occasions prior to 1950 I had the privilege of calling attention at the annual meetings of the American Association on Mental Deficiency to the stagnant condition of the field of mental deficiency. Philosophy, service, classification, research and training -- all were in the doldrums. No one can doubt that the past five years have seen a great change.

New Public Interest

Due in large part to the consolidation of parental strength, the public has been aroused and is more inclined to do some thing about this problem. The American middle-class value orientations have built up in each parent a force that is almost explosive and which in concentration gets things done. These value orientations instill a confidence that we can control nature and therefore can do something about these cases. They put a high value on achievement and hence make it unacceptable that one's deficient child will not achieve. They concentrate our attention on the future, even for those whose future falls short of our hopes. Our values give high place to individualism, yet these must be dependednt and the parent cannot look forward to his emancipation from the child. These are the dams that build up a high potential in the parents and their organization. The result: a new spirit, new laws, new money for research, experimentation and services. There now is a readiness to see treatment as a rational undertaking, even to the point of terminating the state of mental deficiency.

There is danger, however, that our eagerness to enlist public support may cause us to be scientifically careless. Often we hear figures on prevalence beyond what can be substantiated. I have seen no justification for the 4and1/2% not infrequently claimed, and why risk distrust. We are so far behind in our services to the 2% reflected by special school facilities that I would rather not lose confidence by claiming higher prevalence to no avail. There is danger also that some of our values, e.g., the academic, may be forced on children who need something more interpersonal for their development.

The Surrender to Heredity

Fifty years ago the field was saddled with a preoccupation with the impact of heredity. It is not in itself bad to face genetic forces when they are scientifically reasonable, even where not fully validated. This exclusive pre-occupation, however, was fatalistic. It did not lead to an inspection of what in the face of hereditary forces can be done with the experiential forces that always implement or counteract the hereditary predisposition. As a result therapeutic nihilism resulted. The psychological dynamics that we face in dealing with the behavior problems of other children were considered out of bounds for the mentally

deficient. Now this is changing. There is a decline in fatalism about the modifiability of accidents both organic and psychological that produce or complicate mental deficiency. However, let's not be pendulous. Now that we have overcome the shackles of heredity there is danger that we may go too far, deny heredity where it is a factor, and block progress through a one-sided approach.

Therapeutic Optimism

We are beginning to accept the fact that if life experiences by chance can change the 2% of deficient school children to 1% in adult life, we had better use our meliorative forces more designedly. As a pledge of this we are beginning to call our institutions hospitals. However, we have not yet changed the policies of community psychiatric clinics in favor of the acceptance of mentally deficient children and adults. This is serious because it is forcing the establishment of special clinics for the mentally deficient. The clientele of such clinics enter with a presumption arrived at without the assurance of prior clinical service. Will such clinics be chiefly diagnostic or will they offer psychotherapy with other therapies? If so, how will they differ from other clinics? Unless these questions are answered we shall find non-deficient persons trapped in these clinics as they have been in institutions and we shall find opportunities for aggressive treatment neglected. The reversible factors will not be reversed.

Deficient or Not Deficient

If with the knowledge of 1958 we could make a tour of an institution for mental deficiency as of 1928, it would be a very interesting experience. Instead of a group of "bizarre cases" of mental deficiency mixed with the others we would find some interesting cases of childhood schizophrenia such as the child who spent his whole day drawing airplanes in the air wiht his finger, or the one who spent the day standing in one spot looking at his feet until he developed cervical kyphosis, or the boy who went through the motions of shifting gears at every fifth step. We would find cases of autism and of the even more subtle and malignant protophrenia reported in the December 3, 1955, Lance. These cases are not bizarre, but are suffering from a deeply suppressed ego development which seems to go back to family disorder. They behave like the mentally deficient, they look more like quiet normal children but they are anything but normal. Their disorder seems today to be irreversible. We would, of course, find the rocking idiot, but as of 1958 we should recognize that he is a product of his isolation, not directly of his deficiency and we should know that this symptom occurs with isolated normals too. We should be aware that in addition to the deficiency the mentally deficient are subject to the same psychoses and neuroses as we are and also are amenable to treatment. It is significant that some of our elite schools for the mentally deficient have either been converted into services for the mentally ill child, or now serve both and play up the psychiatric treatment of their mentally deficient cases.

The Culturally Deficient

We recognize that isolation happens not only to the mentally deficient person, but also to the familial subcultural case and to his family when it is likewise subcultural. Such a family and its members do not learn the roles and values that prevail in the community and so do not know how to apply effectively such intelligence as it has. Today we do nothing to prevent isolation of such inferior families. One may well question whether, if relieved of this cultural discrepancy, many of these high-grade deficient could not step over the boderline into limited normality. A comparison of children reared in subcultural family with their adopted siblings might suggest how strong a factor family isolation is and at what age and to what extent its effects become irreversible.

Research Has Blossomed

The most startling contrast between the old problem and new view is in the area of research. Ten years ago I visited institution after institution in search of research only to find dust-laden cloths covering laboratory equipment. Today a well designed research with an important objective need not go begging. The Children's Bureau, the United States Office of Education, the National Institute of Mental Health, the Office of Vocational Rehabilitation are financing research and experimentation and priming community services. What we need and too often lack is research imagination to direct these resources into important channels. In addition to federal research funds a number of states have been more liberal in research support.

Neglecting the High-Grade

I should note also that in meeting after meeting concerned with mental deficiency the discussion (and it is a gain even to have live discussion) is focused on the 25% of severe cases, i.e., the neurologically interesting, with almost complete neglect of the higher grades who are the most challenging socially. Pediatricians and obstetricians are not preoccupied with such cases, but psychiatry could do much for them and learn much from them. It is the subcultural children who predominate in the higher grade groups of mental deficiency. Their parents themselves are often of the same type or only slightly higher in intelligence and are not active participants in parents organizations. But when we don't know what to do about these socially crucial cases it solves little to focus on the rare case of severe mental deficiency.

Our Mixed-Up Institutions

The higher grade, three quarters of the mentally deficient, seem to come in for attention chiefly when they do something bad. Then they are taken from the community which has done little for them and placed in an institution which is prepared only to keep them. If this is an institution for mental deficiency

they become a real problem, for in a place that is adjusted to service the low-grade, the aggressive, often hostile, high-grades become a great problem. They are the worldly wise, mixed with the innocent.

Our Piecemeal Planning

This state of affairs comes about because neither nationally nor state-wise have we planned for these cases in comprehensive fashion from conception to death. We have not designed a program and then divided the labor of executing it among our state and local departments and agencies. Instead each department or agency has designed and carried out what it thinks is its job regardless of the whole. There are tremendous gaps. Let me give in skeletal form what such a design would include.

I. During the preconceptual period.
   a. The prevention of conception in cases where mental deficiency is very likely to result.
   b. The alteration of social factors that contribute to the production of mental deficiency in a situation where pro-creation is apt to take place.
   c. Immunization against infections that are likely to bring about mental deficiency.

II. Gestation period
   a. Provision of good obstetrical care of all prospective mothers so as to reduce chance of prematurity, difficult labor and infections and other problems of pregnancy that are likely to result in brain damage.
   b. Continuance of I b and c.

III. Early post-natal period of development.
   a. Case finding.
   b. Medical evaluation and treatment.
   c. Pediatric hospitalization.
   d. Psychological evaluation.
   e. Training and education.
   f. The prevention of social isolation (socialization).

IV. The school age period.
   a. Case finding.
   b. Medical diagnosis and treatment.
   c. Psychological evaluation.
   d. Education based on an evaluation of the individual child and acceptance as a pupil.
   e. Habit training.
   f. Socialization.
   g. Substitute homes and parents, such as institutions, foster homes, etc.
   h. Treatment of emotional disturbance.
   i. Training of work habits.

V. Adult life.
   a. Specific vocational training.
   b. Job finding--sheltered or not.
   c. Economic, personal, domestic and social counseling.
   d. Provision of paternal supervision.
   e. Protection of rights, with constructive adjudication in the case of offenses, or guardianship in case of incompetence.

VI. Old age.
   a. Continuance of economic, personal, domestic and social counseling.
   b. Provision of financial assistance.

Because we have no such design, we neglect the adult deficient and the high-grade case.

Finally let me speak of philosophy. What is a person worth? Who will take the responsibility of putting a price tag on a human being especially if he believes that that being extends beyond a life span and into eternity? But even if only for the here and now, is a life worth spending professional time on in the hope of making it a little better? Is it to be measured only by its value to ourselves here and now, or is its worth inherent? Those who do not try to put on a price tag seem to be best moved to give all that can be given.

GOALS AND DIRECTIONS OF ILLINOIS' PROGRAM FOR THE MENTALLY RETARDED

Otto L. Bettag, M.D.

Interest in the mentally retarded in Illinois encompasses a span of more than 130 years, or almost from the time the earliest settlers were wresting the rich, fertile land from the wilderness.

In the beginning, that interest was passive, rather than active; negative, rather than positive.

In the criminal code of 1827, it was decreed that "An idiot shall not be found guilty, or punished for any crime or misdemeanor with which he or she may be charged."

In 1838, some of the "poor laws" were applied in behalf of retarded children, who then and for many years after were termed "idiotic."

These were the initial legislative evidences of interest. It was not until many years later that a more positively helpful approach to the problems of mental retardation began to crystallize.

A SIGNIFICANT STEP FORWARD

Medical superintendents of the Illinois School for the Deaf, established in 1839, and the Illinois Hospital for the Insane, established in 1847, protested that "feeble-minded" persons were being sent to their institutions in the mistaken belief that their speech or behavior problems stemmed from deafness or mental illness.

In 1855, the State Medical Society took official cognizance of the problems, establishing a committee to "memorialize the legislature with regard to additional provisions for the insane, and the establishment of an institution for idiots."

In February of 1865 - the month before Lee surrendered at Appomatox - the General Assembly passed "an act to organize an experimental school for instruction and training of idiots and feebleminded children in the state of Illinois." The school was established at Jacksonville, under direction of the trustees of the School for the Deaf, with an initial biennial appropriation of $10,000.

As small as that beginning may seem, it was a significant step forward. It marked the first positive move toward special state help for our mentally retarded.

FIRST EMPHASIS ON TRAINING THE TRAINABLE

In 1872, this "experimental" unit was incorporated as a separate school. In 1875, plans for a permanent institution were drawn and in 1877 the institution at Lincoln was opened.

This school was originally established "for children between the ages of 10 and 18 who are idiotic or so deficient in intelligence as to be incapable of being educated at an ordinary school and who are not epileptic, insane or greatly deformed." Patients were accepted only if they were able, in some measure, to help care for themselves.

This point bears emphasis. The function of the institution was considered to be the training of those who seemed capable of some social adjustment following such training. No provisions were made for custodial and nursing care for severely retarded types.

OVERCROWDING ALWAYS A PROBLEM

As in our state mental hospitals, the problem of overcrowding has always existed. From the very beginning, applications for admission far exceeded the school's capacity.

In 1874, the superintendent of the Jacksonville "School for Idiots and Feebleminded Children" complained that the institution, which then had 103 pupils, was extremely overcrowded and that there were over 3,000 other such individuals in the state not receiving care.

This same problem continued with opening of the new school at Lincoln. It seems the unvarying history of state mental insitutions, in all other states as well as in Illinois, that available facilities fall far short of existing needs.

SHIFT IN MAJOR FUNCTION

In 1915, a law for care and detention of feebleminded persons was enacted. Under this law, admissions to and releases from the state institution became the function of the county courts. The institution had no voice in determining eligibility unless and until overcrowding necessitated a waiting list.

This resulted in flooding the institution at Lincoln with large numbers of lower type patients unable to help care for themselves. Inevitably, because of facility limitations, the major function of the institution shifted from training to custodial and nursing care, without removing the need for providing training for those in the upper levels of mental deficiency.

Court control of releases also placed an unnecessary burden upon available facilities, requiring lengthy court procedures before individuals deemed ready for release could be discharged. It was not until October, 1949, that superintendents were authorized to make absolute discharges without prior recourse to court action.

SUPERINTENDENT'S MESSAGE

In 1918, in his biennial report, Dr. Thomas H. Leonard, superintendent at Lincoln, made this statement:

"There should be established as soon as it is possible to do so another institution serving the northern part of the state. The present institution at Lincoln has a proper capacity of 1,600 with 2,265 present. It is so overcrowded that we have been obliged to refuse to accept further commitments."

The institution at Dixon had just begun to function as a state colony for care and treatment of epileptics, the first patient having been received on May 1, 1918. Over a year later, less than 100 "improvable and not insane" patients resided at Dixon.

In view of the serious overcrowding at Lincoln, the director of public welfare ordered, on July 1, 1919, that the name of the institution be changed to "Dixon State Hospital" and that it also admit mentally deficient patients.

SUPERINTENDENT'S QUESTION

In that 1918 report, Dr. Leonard also made this significant observation: "We will not be able to build fast enough to house all the feebleminded of this generation; then, if some must stay in the community, should the state help with the problem?"

In 1920, Dr. Leonard's successor, Dr. C. B. Caldwell, had this to say: "Owing to the fact that it is manifestly impossible for the institution to care for more than one-tenth of the mentally deficient population in our State, it devolves upon other agencies to give these mental deficients outside the institutions such training as will best fit them for a place in life. This means that eventually the public schools must have rooms set aside for the instruction of subnormal pupils."

Time has emphasized the truth of those observations; has made increasingly urgent the need for properly planned programs at the local community level. Today, the combined resident population at Dixon and Lincoln exceeds 10,000, and the problems of overcrowding and large waiting lists still exist.

LOCAL ACTION

It had long been recognized, of course, that mentally deficient pupils do not receive maximum benefit from general education courses designed for normal students.

The Chicago Board of Education's annual report for 1900 carried this statement: "There will always be found in the school system a class of pupils who are so backward that they gain little or nothing from the ordinary course of instruction and whose presence in the general classroom is detrimental to the remaining pupils but who are not yet so deficient mentally as to justify sending them to the State Institute for the Feeble Minded."

Chicago pioneered in action to meet the special education needs of mentally retarded pupils, establishing its first "ungraded class" in 1900. Other public school systems followed, such as Peoria in 1912, Elgin in 1913 and East St. Louis in 1919. Gradually, other communities followed example, but the need for local special education facilities has not, even yet, been fully met.

SPECIAL EDUCATION LAW

It was known that, while their natural intelligence cannot be increased, the vast majority of the mentally retarded are either educable or trainable. It was recognized that not all require or particularly benefit from institutionalizing.

These facts pinpointed the need for special education facilities at local levels. As the years passed without enough of those facilities, those facts pointed up the need for state aid to develop and maintain special classes for educable and trainable mentally retarded within local public school systems.

In 1943, the 63rd General Assembly passed the "Special Education Law for Educable Mentally Handicapped Children." Under the law, public school districts establishing special education facilities for educable mentally retarded children are reimbursed, within specified limits, for the excess costs of such programs.

More than 7,000 educable mentally retarded children are now benefiting from such special classes, but many more remain in need of them. One of the most

important goals in our state program for the mentally retarded is development of adequate special education facilities at local levels.

Between the "educable" and "totally dependent" is another group of children whose degree of mental deficiency is such that they cannot profit from academic programs, but who have limited potentialities for learning to care for themselves, for social adjustment in the home and neighborhood and for acquiring, through proper training, some degree of economic usefulness.

In 1953, the 68th General Assembly enacted legislation designed to help meet the needs of this group. This legislation enabled public school districts to establish special classes for "uneducable but trainable children," providing for reimbursement of two-thirds of the special teachers' salaries when prescribed conditions are met.

Today, state-aided classes embracing more than 300 trainable mentally retarded children are functioning in school districts throughout the state. And thus, through these education-and-training programs under jurisdiction of the state Superintendent of Public Instruction, the state is affirmatively answering Dr. Leonard's 40-year-old question: "...then, if some must stay in the community, should the state help with the problem?"

COOPERATION AMONG STATE AGENCIES

The cooperation among state agencies concerned with any aspect of the problem of mental retardation is excellent. This cooperation extends to and benefits all concerned with community effort in this field.

The Institute for Research on Exceptional Children was organized in 1952 at the University of Illinois. In addition to functioning as an inter-disciplinary unit within the university, it functions as an inter-agency instrument between the state Department of Public Welfare and the Office of the Superintendent of Public Instruction.

Working in close cooperation with these agencies are the Division of Vocational Rehabilitation, the Illinois Psychiatric Advisory Council and the Illinois Psychiatric Training and Research Authority. The latter two bring the state's outstanding psychiatrists and representatives of the Illinois medical schools actively and continuously into the program to combat mental retardation.

The Commission on Mental Retardation, activated in September, 1957, when Governor William G. Stratton appointed 13 members who have already demonstrated great vision and dedication, will undoubtedly play an increasingly important role. This commission is unique, to the best of my knowledge, in that it is the only state commission which functions without a special appropriation.

KNOWLEDGE MUST BE APPLIED. . .

These various agencies and special committees are helping to add, in many ways, to our existing knowledge concerning mental retardation. But knowledge, as I have said before, is like a hot poultice...it must be applied to prove its value.

Most of the knowledge we now possess on this subject can best be - and should be - applied at local community levels, or at least at the closest practical level of community association.

Conferences like this can be a tremendous influence for good. That influence can best be realized, in my opinion, by working to develop a full recognition and acceptance of individual responsibility for community action.

"THE ESSENTIAL MORTAR OF COMMUNITY ACTION"

Let me share with you a very thoughtful statement made some years ago by Governor Stratton.

"Families," he said, "are the bricks of our social structure, and are individually as strong or as weak, as the bond between parents and children. But however strong the individual brick may be, unless it is properly aligned with the surrounding bricks, and unless all are firmly linked, strengthened and protected by the essential mortar of community action, our entire social structure is endangered."

Think about that...its truth will "grow on you," I believe, as it has on me. It is just as true in relation to the problems of the mentally retarded as it is to any other public health or welfare problem.

VALUABLE COMMUNITY SERVICES

There are many private and semi-private organizations already making important contributions in this connection. The Illinois Council for Mentally Retarded Children, a non-profit organization, is doing much to stimulate public interest in the problem. Many of its affiliated groups, approximately 60 in number, are providing day care services, sheltered workshop programs and other important assistance at local levels.

Legislation passed by the 70th General Assembly extended the welfare department's inspection and licensing responsibilities to include day care centers for the mentally retarded. Initial surveys indicate that there are more than 40 day care centers throughout the state exclusively ministering to the needs of the mentally retarded, and many others which include the mentally retarded in general day care services for children.

Since it is estimated that there are approximately a quarter of a million mentally retarded and slow learners in the state, it must be obvious that there is great need for many more local services of this kind.

THE STATE SCHOOLS

Today, the more than 10,000 resident population at Dixon and Lincoln includes individuals in all classifications of mental retardation, ranging in age from a few months to 92 years. More than 1,350 others, almost half of them children, are on the waiting lists for admission.

Our first responsibility to this resident population involves custodial care. Before - and whether or not - there is opportunity for education and training, we must meet their needs for food, shelter, clothing and the other basic health and security requirements.

Ideally, our objective is to prepare the individual for return to the community. Actually, since the lengthy waiting lists force us to accept as admissions mostly those in the lower levels of mentality, we do not achieve this objective except in a

very small percentage of cases. Nonetheless, our programs at Dixon and Lincoln must be geared to realize the individual's potentialities for self-help, socioeconomic adjustment and ultimate return to his or her community.

OCCUPATIONAL, RECREATIONAL, INDUSTRIAL THERAPY

For that reason, these programs include occupational, recreational and industrial therapy; an ungraded school; band and choral groups and numerous other activities aimed at developing the students' social and economic potentialities.

We are proud that our activity therapies program has received national attention. I wish to pay tribute to Miss Bertha Schlotter, chief of activity therapies for the department. She helped organize the recreation department at Lincoln state school in 1929 and was its first chief. She is author of the popular text entitled "Experiment in Recreation."

FAMILY HOLDS THE KEY

We recognize that the family holds the key to the mentally retarded child's future. We recognize, also, that this key may lick as well as open the door to a better future.

When the home environment warrants it, the individual released from a state school is returned to the family group. But long before such release, our social workers have carefully investigated the environment and worked with members of the family to prepare them for their responsible roles.

As important as it is, love alone is not enough. Not infrequently, the almost fierce, blind love of a parent results in overprotection that tends to perpetuate dependency. Love must be thoughtful and realistic, untainted by possessiveness, demonstrated by intelligent action. Such love has a value beyond measure.

FAMILY CARE PROGRAM

Where the proper home environment does not exist and cannot be developed, we seek to place the individual in a foster home. In such cases, the same careful study of environment is made, with the needs of the mentally retarded person the paramount consideration.

This is known as the "Family Care Program" and is just what the title implies... a realistic attempt to provide the essential elements of good family care, including affectionate and intelligent attention to the special needs of the individual.

As an extension of this program, supervision and assistance are given to those individuals who attain an even greater degree of social and economic self-sufficiency.

Supervised boarding home placement, wage placement, counseling and the many services necessitated by the special needs of the mentally retarded are included in this "Family Care" program. Always, there is active, beneficent and competent supervision and every possible assistance.. never is the individual sent into the community alone and friendless.

THE "HALF-WAY HOUSE" PROGRAM

Another important step forward is being made with construction of "Half-way

Houses" at Dixon and Lincoln. These "half-way house" programs are planned to facilitate the transition from institution to community life. Intensive training and conditioning will be given to selected individuals in surroundings differing importantly from the regular institutional climate. It is expected that this program will help the selected individuals take the step into normal community life more confidently and capably.

PARENTS AND VOLUNTEERS

We are extremely fortunate in having active Parents' Associations and excellent volunteer services programs at both Dixon and Lincoln. The contributions of the parents and volunteers are hailed by all personnel, and I must take this opportunity to express the department's and my gratitude.

To the fullest possible degree, return to the community is ever our aim. Is it not only wise, but necessary, then, that we explore and utilize every possible means to help the mentally retarded at the community level?

BETTER SERVICE TO ALL

Let no one believe that this means that we can ever dispense with state schools for the mentally retarded. It can mean, however, better service for those who do require special institutional service as well as for those who do not.

It would mean, also, elimination of the pressures, tensions and frustrations which inevitably accompany overcrowding, understaffing and lengthy waiting lists.

We are not placing exclusive emphasis upon community action. We seek to achieve that proper blending of local-and-state services which will best meet the needs of the mentally retarded, thus serving the best interests of all persons in the state.

MENTAL HEALTH FUND

Our needs within the state services primarily center around problems of overcrowding, due to shortages in buildings, which is a problem we share with all other states. Overcrowding and consequently inadequate facilities also seriously hamper our efforts to recruit and retain qualified personnel, another national problem. In addition, there is the problem of insufficient knowledge, which can only be resolved through research.

Thanks to the Mental Health Fund, established in 1951, important strides toward solution of these problems are being made.

TWO IMPORTANT INSTITUTES

Perhaps you have had an opportunity to view the exhibits set up for this conference. If so, you will have seen the architects' depiction of two very important institutes which will soon be standing side by side in the state's famed Medical Center District in Chicago.

TREATMENT, TRAINING, EDUCATION AND RESEARCH

In that district, the department will combine the most modern facilities for treatment, training, education and research relating to mental illness and mental retardation.

The 432 bed, eleven story, $9,500,000 Illinois State Psychiatric Institute, for which ground was broken on October 19, 1956, will be ready for occupancy early in 1959. Adjoining it will ultimately be a 600 bed pediatric institute for mentally retarded children up to the age of six years, for which $5,500,000 was appropriated by the 70th General Assembly.

It is important to note that these institutes are being constructed with Mental Health Funds, which are derived from payments for patient care and maintenance in our state mental institutions, and not from General Revenue funds.

In addition to placing urgently needed treatment facilities in the heart of the state's most heavily populated area, these institutes will work with the state's medical schools to further the education and training of medical students and other professional personnel in serious short supply. The research facilities will constitute important additions to those already in existence.

ADVANCES AND IMPROVEMENTS

We have made - and are making - advances and improvements all along the line...both at local and state levels of service. As we move in the direction of our goals, we have the advice, counsel and whole-hearted assistance of the best minds in the state.

We have mentioned many. There are many more who should be mentioned. I hope it will suffice to say that we are deeply indebted to all, and have faith that collective effort of the type now being undertaken will return huge dividends in the form of healthier, happier, more reasonably self-sufficient individuals.

This conference, enabling us to pool the knowledge, wisdom and experience of five states, is an important step in the direction of our common goals. I sincerely hope that all of us - and all of those we serve - will derive maximum benefit from it.

GOALS AND DIRECTION OF THE INDIANA PROGRAM FOR THE MENTALLY RETARDED

S. T. Ginsberg, M. D.

Transition is probably the most prominent characteristic of the field of mental deficiency today.

Many aspects of the field are changing; for example, community attitudes, community facilities, parent attitudes, methods of management, the nature of the mentally retarded populations, particularly that within the institutions.

Historically the State of Indiana has assumed the responsibility for the care and treatment of the mentally retarded since the earliest days of social legislation. The Fort Wayne State School was established in 1879, but did not receive its first patients until 1890. The original bed capacity was 300 and the first residents were transferred from the Indiana State Soldiers and Sailors Children's Home at Knightstown, via the Richmond State Hospital where they were temporarily housed due to a fire at Knightstown.

The school was initially designated as the Indiana School for Feebleminded Youth and changed to its present name in 1931. The need for an additional facility became apparent soon after the turn of the century, and a branch was established at Butlerville, Indiana, in 1919, which was originally called the Farm Colony for the Feeble Minded. This was changed to the Muscatatuck Colony in 1931, but stll operated as a branch of the Fort Wayne State School with one Board of Trustees. In 1941 the name was finally changed to the Muscatatuck State School, and became a separate and distinct institution serving the southern half of Indiana.

The original designation of a school for feebleminded youth was somewhat of a misnomer, as adults were admitted from the earliest days. Early legislation established a commitment procedure for feebleminded persons between the ages of six and sixteen, and the cost for maintenance was decided by law. In effect, the schools for the mentally retarded in Indiana, from their inception, serve all persons, regardless of age, who are in need of these specialized facilities.

A further review of the original legislation also reveals some interesting facts concerning the purpose and operation of these institutions. Originally stated, "The purposes of this institution shall be to care for, support, train and instruct feeble minded children. The institution is to be divided into two distinct departments: one industrial, the other custodial. The industrial department is to be a department for culture, in which shall be placed such feeble minded children who are actually, in a practical sense, capable of improvement, in which the rudiments of a common school education are to be taught, in connection with, and subordinate to, culture in manual and industrial occupations. The objective point to be obtained in this department is future usefulness, self-care and self-support. The custodial department shall be an asylum for low grade, feeble minded, idiotic, epileptic children. In this department, special attention shall be paid to mental, physical, and gygienic treatment."

While none of us here would be pleased or proud to accept these statements as our goals today, a careful study reveals much of what is still considered the essential elements of the overall program. Our forefathers, with extremely limited knowledge and understanding of the problem, had many noble ideas and presented a somewhat positive approach to the treatment and care of the mentally retarded.

Education and training were primary goals. Return to the community for useful and self-sustaining occupation were formost in their minds. Permanent custodial care was considered only for those who appeared to be hopelessly retarded and beyond even simple habilitation. For such bold legislation and purpose, none in Indiana can find fault. Whether sufficient funds and trained staff were ever made available to accomplish these goals is a moot point. We do know that full realization of these goals were seldom obtained and the successful training of even the most educable were at best minimal.

In 1953 Indiana took a new look at its mental health program, including mental retardation. A central office was established with full authority to direct and coordinate the treatment services of all mental hospitals and schools for the retarded. Increased appropriations made possible the employment of large numbers of additional staff, both professional and sub-professions. The American Psychiatric association was asked to conduct a survey to determine Indiana's mental health needs.

The results of this survey indicated that Indiana was fairly consistent with the national average of incidence of mental retardation, estimated as one percent of the population. Using an established formula that about ten percent of this group has mental deficiency sufficiently severe to require institutionalization, an approximate resident bed capacity of 4,000 would be needed. This is about the number of patients presently enrolled in our schools. Were it not for the extreme over-crowded conditions at our two schools, estimated at from 25 to 50 percent, additional facilities would not be required. Even with the overcrowded conditions, Indiana took a calculated risk and put her confidence in more personnel and more effective treatment techniques, and not in additional facilities. Whether this decision will prove to be prudent, still remains to be fully demonstrated.

The survey clearly pointed out that Indiana, like most states, was expending the bulk of its treatment dollar toward the care of the long term, chronic, and prognostically unfavorable cases of mental illness and mental retardation. A very small proportion of the financial outlay was devoted to the facilities needed for early diagnosis, referral and intensive treatment. The key question was: What can Indiana do to reverse the upward trend of a growing patient population in institutions for prolonged care? The answer, it was suggested, does not lie in following the patterns that have characterized the approached of the past century. It must rather lie in a refocusing of effort to develop a network of facilities for the early intensive treatment and training of the mentally retarded both in and out of the schools. Some specific recommendations were: establish intensive treatment units in all state hospitals and schools; initiate training programs for all professional categories in each unit, in cooperation with appropriate professional schools; expand vocational rehabilitation services to all who can profit from this program; expand family care and foster home care for those patients who need a proper home upon discharge; establish adequate research facilities.

Three years have elapsed since the completion of this study. While there is always a time lag between recommendation and action, many of these recommendations are in various stages of accomplishment. Both schools have established intensive treatment and training centers. Medical care and direction, so often neglected in mental retardation, is rapidly improving. An increasing number of physicians are being employed on a full-time basis. A larger number of medical consultants are employed. Diagnostic and evaluation staffs are conducted upon patient admission and in some instances prior to admission. Complete physical examinations are conducted on all newly admitted patients, and periodically for all patients. Corrective

and remedial action are taken promptly whenever indicated. Emotional disorders are treated locally whenever possible. Transfer to a mental hospital is promptly ordered where more intensive and specialized treatment is needed.

This represents considerable progress in the medical care of the mentally retarded. It does not, however, reach the full potential of a concentrated program of psychiatric treatment. The problem of mental retardation, I am firmaly convinced, is a medical problem with considerable psychiatric overtones. It is estimated that somewhere between 50 and 80 percent of the mentally retarded in institutions have psychiatric problems.

It appears quite likely that mental retardation could definitely be construed as a field for active neuropsychiatric endeavor. The psychiatric team approach (active psychiatric treatment with psychotherapy, group theapy, neurological study, ataractic drug therapy, milieu therapy, education and rehabilitation) in a psychiatric setting has been found to be, where actively and diligently applied, very successful in the treatment of mental illness. It would seem, therefore, that these proven techniques should be found very useful when actively applied to the problems of the mentally retarded and their families.

I do not underestimate the need and effectiveness of the many other disciplines serving the mentally retarded person. Without a full inter-disciplinary approach little or no progress could be made. Emphasis on diagnosis, evaluation, treatment, education and rehabilitation may not be neglected. Our Indiana program places great emphasis on the use of all disciplinary approaches to the problem.

Let us try to analyze the transition occuring in the field of mental retardation. Such an analysis is difficult in an exact science, but is much more complex in a social science such as public health.

The rates of change in Indiana appear to be particularly rapid. Within the past five years, populations of state schools have been re-evaluated in the light of rehabilitation and many of the higher functional and misclassified patients have been returned to the community. This positive approach has been accompanied by a lessening of emphasis on other negative aspects of the management of the mentally retarded, including sterilization, lifetime incarceration and the failure to apply psychiatric diagnostic criteria which would separate the mentally retarded from the psychotic, from the criminal sexual psychopath and from other character disorders with anti-social trends. At the same time there has been an increase in the special education facilities within the school systems of the cities and towns. In Indiana, so far, the efforts have been directed mainly toward educable children; but with changing public acceptance and the open, concerted efforts of the parents' organizations, educational facilities are becoming more available for the trainable mentally retarded as well.

To proceed any further with an analysis we must consider separately the two main groups into which mentally retarded persons can be simply divided. The first group, usually referred to a familial, represents over one and one-half percent of our population at the lower end of distribution on the normal curve. It is important to keep in mind that these are normal persons who come under our consideration because they deviate enough from the average of our population to require special management. In a state like Indiana with a population of 4,000,000, we have some 60,000 persons in this group. Obviously the population of our two state schools includes only a small fraction of them at any one time.

It is appropriate to ask the question, "Why are certain persons of this group in the State schools when the majority spend their entire lives in the community making an adequate adjustment?" Many years ago the answer to this question was that only in the State school could these persons find the special education classes which they require during their school years if they are to advance at their reduced rate toward the third, fourth or fifth grade level of performance of which they are capable. Today, with increased educational facilities in the communities, the answer must be modified. Even the most cursory analysis of our case records will show that commitment is dependent upon other factors in addition to mental retardation. The indications for admission are in a great majority of cases social reasons. These normal persons of low intelligence fail in their community adjustment for precisely the same reasons as other normal persons of average intelligence may fail in their community adjustment. The fact that a person is mentally retarded does not protect him from being subject to behavior disorders of childhood, character disorder, severe psychoneurosis or a frank psychosis.

The numbers of familial mentally retarded are not increasing in our population so far as we know. The genetics are not completely understood, but most cases represent multiple factors.

Within the institution, however, the familial group is decreasing. Administrative staffs in all state schools are faced with a gradually decreasing average level of functioning in their patients. The higher functional patients, who continue to be admitted, come because of some psychiatric disorder or for socio-economic reasons. In many cases they are treatable, so that with training, and as they increase in maturity of judgment, they become capable of returning to a self-supporting, productive life in the community. Much more needs to be done in providing special education facilities and recreation facilities within our public schools and communities toward the end that the vast majority of these higher functional retarded persons can remain with the other normal persons in the community of which they are a natural part.

The second large group of the mentally retarded are the pathological cases which make up about one-half of one percent of our population. They consist of those persons who have suffered some accidental brain damage either before birth or at the time of birth or after birth. The damage may have resulted from a great variety of causes, including central nervous system infection, anoxia, trauma or intra-uterine maldevelopment. These persons would presumably have been distributed within the average range of intelligence except for the damage to the central nervous system. But following the central nervous system damage the intellectual function is disturbed, so that the average of the group falls in the severely retarded range. Their central nervous system defect may also result in cerebral palsy or convulsive disorder, so that children whose central nervous system damage had identical etiology may on the one hand have their mental deficiency over-shadowed by their motor deficiency, while others may have seizures so frequently that their epilepsy is the main management problem. It is readily apparent that the populations of State schools and of State hospitals for the epileptic have a tremendous overlap in the patient load which they serve.

The pathological group also includes a small subgroup of genetic cases where the defect is determined by a single gene, in some diagnoses a simple recessive, in

others a simple dominant or a sex-linked recessive. This subgroup is small but contains some of our most fascinating examples of metabolic disorder and probably should include many cases of prenatal defect of unexplained etiology, particularly cases of congenital cerebral palsy. Also among the pathological group are more common clinical entities such as Mongolism in which the etiology is poorly understood.

The pathological group, which contains most of our severe and moderately retarded persons, has increased rapidly in the past 15 years. This is not a result of more of such children being born but a result of more of them living to an older age. Many brain damaged children, frequently premature, are resuscitated and with the improvements in pediatric care, feeding, and control of infectious diseases, now have greatly increased life expectancy. Their numbers are rapidly increasing both in the community and in the institutions.

This increase has resulted in a social pressure which has forced State schools to develop large facilities for the care of severely retarded infants. Some of them are so severely retarded that they require the care of an infant throughout their lives. Others, who may reach a mental age of between four and seven years (a group where Mongolism is a conspicuous diagnosis) are ambulatory and trainable. This group presents a tremendous challenge to persons working in the field of mental deficiency for the development of a program suited to their needs. Never present before in the community or in the institutions in such large numbers, their requirements for a lifelong program have never been given the special consideration which is warranted today.

Before these persons became such a prominent part of the mentally deficient population, most State schools had a minimum age for admission of six years. With the availability of nursery facilities early institutionalization of severely retarded infants was recommended. Before long the available facilities for young children were over-crowded and long waiting lists built up. We are at this point today. The impracticality of recommending early institutionalization is evident. Beds cannot be created at a rate which will meet the demand and serious consideration must be given to the advisability of recommending admission for young infants. It is dangerous to generalize on this point. Studies of the long term adjustment of parents, siblings and retarded child himself need to be made to derive some objective data on what is the wisest course. It must always remain true that each case should be considered individually in terms of the personalities of the parents and siblings, the position of the retarded child in the family, the social attitudes of the parents toward institutionalization, etc. Much has been made of the ill effects which the retarded child may have on his siblings; but detailed family studies are not available to support such conclusions. When the public facilities are not available the crippling effects on the family economy from the expense of private care may far out-weigh any harmful emotional effects a retarded infant may have on his siblings.

Just as there is no sharp line of demarkation between mental illness and mental health, or mental retardation and the intellectually normal, there is a bordering area of mental deficiency. I refer to those mentally retarded who may have a severe character disorder with sociopathic behavior. These are sometimes referred to as defective delinquents, representing an almost unmanageable type of patient in the present day school for the mentally retarded. These are frequently refused by the Training Schools in the Department of Correction and are reluctantly admitted by the school for the mentally retarded.

Indiana is in critical need of facilities for the defective delinquent where adequate

psychiatric, educational, vocational and recreational programs can be brought to bear on those individuals who can be rehabilitated, and where other individuals can be cared for until some of their stronger sociopathic trends "burn out" and they become better risks for life in the community. These might be called "no man's patients".

Other types of "no man's patients" are the mentally retarded with addional sensory defects such as blindness, deafness, deaf-mutism, aphasia, etc. These persons are relatively small in number but rarely have their special needs been met. Frequently they will shuttle back and forth between the School for the Blind or the School for the Deaf, which lack facilities for teaching these children with double handicaps. Some one of these institutions must be designated as the responsible facility for their care, education and treatment, and that institution must be provided with the special facilities and the trained staff to meet their special needs.

A similar problem exists in the management of those mentally retarded persons with a psychiatric disorder. It is rare to find a mental health clinic in the community which will accept mentally retarded children and their parents in the treatment case-load. Frequently the child guidance centers limit their service to a brief diagnostic encounter and reject the case as soon as mental retardation is recognized. This may be in spite of the fact that some treatable psychoneurotic disorder, psychotic reaction or situational maladjustment is the presenting problem rather than the mild mental retardation. The mental deficiency was present in the child even during his period of adequate social adjustment prior to his decompensation with the super-imposed psychiatric disorder. Sometimes a patient is diagnosed Mental Deficiency with psychosis by a State hospital and transfer to a State school requested. On the other hand the same patient in the State school might be labeled Psychosis with mental deficiency and an effort made for his transfer to a State hospital. This shuttling of patients between State hospitals and State schools has lessened with the increased recognition of psychiatric treatment as a service function of a State school; but there is still a great need for increased understanding and acceptance of the mentally retarded for treatment by psychiatrists in general.

This brief look at the two groups of mentally retarded who require different management and at the changes that are rapidly taking place points up the need to focus our efforts on the community management - educationally, socially and psychiatrically - of the higher functional group and to direct our efforts toward research on the causes and methods of prevention of the pathological group where in most cases cure is impossible. For the lower functional patients research must also be directed at a better understanding of their potential for training and self-care as adults and for a more adequate program within the State schools to meet the needs of the moderately retarded who are gradually becoming the majority group in the State school population.

In our institutions nursing care is an integral part of medical treatment and an indispensable tool in the care and treatment of the mentally retarded. The nurse has a dual function. She is responsible for the traditional clinical services, such as the administration of medication and improving the hygiene of the patient. She also is responsible for ward or cottage management, including the training and supervision of the psychiatric aide. The nurse also must be skilled in handling behavior problems and serve as a resource person to the aides and other staff members who need assistance in understanding the individual differences of mentally retarded

patients. More time and energy could be devoted to the training and education of the psychiatric aide, particularly in the area of simple nursing procedure and the establishment of a therapeutic cottage environment.

Another essential service to the development of an effective treatment program is in the area of psychiatric social work. The social worker is personally involved with the patient and family prior to admission, throughout the institutionalization period, and in varying lengths of time after leaving the school. No other member of the clinical staff is as closely involved with the family, and the successful disposition of the patient often hinges on the skill of the social worker.

Increased numbers of qualified psychiatric social workers will assure more effective pre-admission evaluation. More intensive work with community agencies will help resolve many problems before admission and keep border-line cases functioning in local facilities without institutionalization. Proper guidance and consultation service to community agencies should increase the awareness and ability of local communities to properly serve the retarded person and family by making available more resources for evaluation, diagnosis and treatment.

A full staff of capable psychiatric social workers can add immeasurably to the intensified treatment program and reduce the gap between treatment and discharge. Discharge planning started early enough should increase turnover and reduce waiting lists. Active follow-up or after-care services will reduce readmissions and assure maximum utilization of the skills and resources so painstakingly acquired during the treatment and habilitation program.

The training and educational program must be diligently pursued and made a part of every phase of development of the mentally retarded. The outer limits of training and learning are as far from being known for the retarded person as it is for the normal person. New skills and techniques applied by more and better trained special education teachers should be able to increase the limits of learning far beyond what we achieve today.

Training should begin immediately after the medical evaluation is completed and a diagnosis established. Training, like in normal living, should begin at home. The cottage, a home substitute, should serve as the initial focus of training. Self-care at increasing levels should be the first goal to be achieved. The school program follows with increasing amounts of challenge and ceases only when the individual graduates back to the community or into specialized vocational training or assignment.

Vocational training, so long neglected, or abused under the misnomer of "industrial therapy" is the college or higher education program for the retarded. As the normal individual is required to obtain and achieve more complex skills in a society of specialized industry, many of the unskilled and semi-skilled jobs become available to anyone who can reasonably adjust to the demands of society. There are endless opportunities opened for the large number of our patients who will never achieve high vocational skill. The vocational training of the mentally retarded is still in its infancy. Comparatively little is known about the full potential of these individuals and methods for successfully teaching skills at various intelligence levels are almost completely lacking. Recently the Muscatatuck State School was successful in obtaining a financial grant from the office of Vocational Rehabilitation to support a demonstration project in vocational rehabilitation. Methods of teaching will be carefully recorded and successful experiences correlated with technique. We will watch this study carefully and incorporate the successful practices in our permanent program.

One of the rewards of labor is leisure time. All people have need for relaxation and opportunities to participate in pursuits without consideration of monetary gain. The mentally retarded individual must have continued training and education in the healthful use of leisure time. This is particularly significant when we recognize that the retarded individual often goes astray when he is completely left to his own devices. He is easily swayed and lead, and often the victim of unsavory individuals. On a job there is usually supervision and direction and less opportunity for unwise judgments. In leisure there is freedom, and choices must be prudently made and companionship carefully selected.

One of the primary goals in a program of recreation for the mentally retarded is the teaching of skills and the establishment of values in a variety of socially acceptable leisure time pursuits. Great care must be taken to assure participation in endeavors which are geared to the level of the patient. Successful experiences are necessary to assure the formation of good habits and the continuation of selection when left to make their own choice. Community facilities with trained leadership are usually available. The Fort Wayne State School recently has entered into an agreement with the local community recreation authority, as a demonstration project, whereby the community facilities and staff will be available to the patients of the School. There will be mutual orientation. The goal is to gain experience with the retarded while still in the School so that the community will accept full responsibility after discharge and improve the program of recreation for all handicapped.

The clinical psychologist who has for so long carried a heavy load in the treatment program, is an indispensable person on the clinic team. He is active during preadmission evaluations furnishing diagnostic tests and collateral information. His services are utilized throughout the treatment program and are becoming more active in group psychotherapy, play therapy and vocational guidance.

Other therapies are employed with increasing success, such as speech and hearing therapy, occupational therapy and physical therapy. These specialized adjunctive therapies have proven remedial values which contribute immeasurably to the treatment program.

Another valuable asset in the development of an intensive treatment program to promote full habilitation is the utilization of volunteer services. The volunteer serves a dual role in our program. She brings to the school a bit of the community and breaks down the barrier between institution and community. Often she has talents useful in many of the disciplines serving the patient. She can truly bridge the gap and facilitate return to the family and community. Another important role is in the education of her friends and neighbors. No lay person is better equipped to promote interest and understanding within the community than the person who is personally involved in this work. The volunteer has been extremely successful in supporting necessary legislation, and I look forward to the day when they will exert an even greater influence on the public and the legislature.

Now let us take a look at the future. Where are we going? What is our direction? What can we do to help reverse the increasing numbers of people requiring institutional care?

The social and economic problems of mental retardation are too complex to be answered solely by institutional segregation. It is necessary to have programs outside the institution. This is the greatest need in our state, and probably elsewhere.

We need programs of early recognition, diagnosis, medical treatment when indicated, testing, guidance or counseling for both patients and families, special education classes, and foster home placement when needed.

The full realization of this community program cannot be accomplished by the Division of Mental Health alone. It requires the development of a comprehensive program in coordination with the Departments of Health, Education, Welfare, Vocational Rehabilitation, social agencies, private schools, the medical and other professions. With the wholehearted development of supportive community resources, a large number of those mentally retarded presently requiring institutionalization could be beneficially cared for within the local community, and not require the traumatic separation from family and friends. To this end we must strive with all our resources.

Another area in which I put a very high priority for future development and direction is the field of research. In the final analysis, it is only through research that mental retardation will eventually be eradicated. Research in all areas should be vigorously pursued. Basic and fundamental research to develop more effective treatments for the types of retardation for which a cause is known. Administrative research to promote the efficient use of personnel, develop appropriate personnel-patient ratios, and improve operational procedures in schools and clinics. Epidemiological research, to determine the incidence and distribution of specific types of mental retardation in various population groups and types of communities, and to explore the reasons for this incidence and distribution.

Continued improvement in the medical and educational services and all allied disciplines shall always retain a high priority and needs our concerted effort to assure the best services available within the scope of present knowledge.

Society faces a tremendous responsibility in caring for many of these relatively helpless children who have increased in number as a by-product of the advances in medical treatment. They deserve the same care as any other and should have the same opportunity to enjoy life to the full limit of their capacity. Their management, education, treatment, and rehabilitation may be taken as an index of the social maturity of our culture. I am truly looking forward to this workshop to serve as a source of practical and fundamental information which can be readily applied to improve the program for the mentally retarded in the State of Indiana.

GOALS AND DIRECTION OF THE MICHIGAN PROGRAM FOR THE MENTALLY RETARDED*

V. A. Stehman, M. D.

The goals and the directions of the treatment program for the mentally retarded in the State of Michigan seem to be in general accord with newly developing programs throughout the country. We view the primary function of the institutions for the care of the mentally retarded to be one of education and re-education, along with a program of rehabilitation that aims at a mixiumum social adjustment, first within the hospital, then within the home, and ultimately in as many cases as possible a productive role in society. This implies a vocational training that will permit the patient to be partially or fully self-supporting. Any detailed reporting of this program would involve a minute description of all of the activities of any of our institutions, starting with basic medical care and treatment, and running through the total educational theories and programs, the activities of the Department of Psychology, a review of the philosophy governing social case work in the institutions, and the philosophy and techniques underlying vocational retraining programs. It will suffice to say that patients are returned to their homes and communities, and are making good social adjustments, and many patients are being successfully and productively employed, beginning with a few hours of work a day in the communities near the institutions and moving on into full or part time jobs after they have left the hospitals. It is perhaps unnecessary to add that the total numbers are small, but our program is based on the firm belief that the patients in these hospitals can be more productive with better programming, and we are hopeful of returning greater and greater numbers to a productive role.

The greater bulk of our patient load is comprised of severly handicapped individuals with organic lesions and deformities that render them so helpless that a program of good medical and nursing care is all that one can provide. We are striving to expand our medical services beyond the area of maximum care to include clinical research in the medical aspects of mental illness.

We provide fairly classical educational programs for the minimually retarded children, as well as highly specialized educational programs for the severely retarded youngsters who are trainable. It is our goal to have all educable children trained in the public school systems if there are no medical or social contraindications. We feel that educational programs in the institutions should be limited to those individuals who, for various reasons, cannot attend the public school system.

In attempting to determine the best ways to reach our ultimate goals, we are developing a continuing program of clinical investigation and research. At the present time, we are working with a project study in reorganization of our nursing services in which the nursing profession is taking over responsibility for the development of a program of community living in small cottage nursing units. Nursing personnel are being trained in the theory and techniques of such programs, and the specialists in other areas such as occupational therapy, recreation, and education, as well as the psychologists and social workers are being used as specialist consultants who teach nursing personnel various skills that they can apply in the total living situation.

We are planning a project study to investigate family care programs, which all too often are custodial and non-therapeutic.

Basic research relative to the role of anti-vitamins in the development of mental deficiency is being carried on at our training and research center, the Lafayette Clinic.

In our program of inservice educations, we are providing continuing workshops and training programs for all personnel, with particular emphasis at the present time on nursing personnel. In addition to the inservice hospitals in the individual institutions, our universities are providing resource people who are conducting special programs in such areas as personnel management and supervision, child development, child psychology, and other technical subjects related to hospital management and patient care.

In our long range planning, we visualize our institutions for the mentally retarded as providing care only for those who are not able to remain in the community because of medical or social difficulties. We feel that the training of the retarded individuals should be carried out on the community level wherever possible, and the Department supports (but does not initiate or administer) investigative studies and efforts to develop all types of community services such as day schools, educational programs in the public school curricula, sheltered workshops, halfway houses, and other community programs.

We are also studying the feasibility of treating emotionally disturbed children in our hospitals for the mentally retarded and gradually move toward the fulfillment of a concept of children hospitals that will provide a total treatment and living program for all children needing mental health services. Our longer range planning is aimed at the development of increasingly smaller hospital and treatment units that will be community based, and make maximum use of community resources in the treatment of the mentally retarded.

* The Honorable Charles. F. Wagg, Director, Michigan Department of Mental Health, asked Dr. Stehman to present this paper.

GOALS AND DIRECTION OF THE STATE OF OHIO FOR THE MENTALLY RETARDED

W. A. Butcher, M. D.

Dr. Duty who is the Commissioner of Mental Health of Ohio has asked me to substitute for him since he is ill and unable to be here.

I think Dr. Duty rather wisely chose an individual subject to discuss today which is perhaps a little bit unique. I will not, therefore, go into the total program in Ohio simply because as I sat here and listened to the other speakers, the difference between Ohio's program and that in the other states is mainly a difference in dates. For instance the Ohio asylum for idiotic and imbecilic youth accepted their first patient just 100 years ago this year. This asylum since about 1949 has been renamed the Columbus State School. We still occupy the original building on the same ground that was occupied in 1867. As a matter of fact my office is in the original Superintendents living quarters. So our problems are the same. Our programs began about the same time.

This morning when Dr.Stevens mentioned Dr. Goddard I was impressed with the fact that when I first came to the school about three and a half years ago, I read some of the records on some of the patients who were still there and in those records were Dr. Goddard's recommendation that this patient, after a good diagnostic work-up, which Dr. Goddard did, could be placed in the community. In some occasions some 30 years later we accepted Dr. Goddard's recommendation and did place that patient in the community. On the other hand in community placements in the last seven or eight years one institution in Ohio has returned some 2600 or 2700 patients to the community through various programs.

To show that we have similar problems, a couple years ago in one of our Hathaway houses in Columbus we had a somewhat similar experience. We took a little different course. When the taxpayer needled the city of Columbus into doing something about having retarded persons in the community in a home, the city of Columbus sued the operator of that home under a zoning ordinance. With the moral support of my staff and particularly Mrs. Smith who is out in the audience, and the then Commissioner and Director of Mental Hygiene in Ohio, we decided to fight that suit and I am very glad to say that in a common police court in Ohio the judge decided that these persons were not a nuisance to the community in the sense of the ordinance and the county home is operating today and will continue to, I hope, unless they take it to the Supreme Court. We will try again at that level.

In choosing a section of the program in Ohio to discuss for you, Dr. Duty chose the development of the community classes for severely retarded children. We are fortunate in having with us in this audience the gentleman who carried the ball on that program, Dr. Purcell. He has carried the program of community classes in Ohio since its inception.

Now, if you will permit, me I will read for you Dr. Duty's talk.

Since assuming the position of Commissioner of Mental Hygiene for the State of Ohio a few months ago, I have become aware of a program supervised and administered by the central office of this division. This program has copy imagination and interest of almost all citizens living in practically every city and hamlet in our state

of approximately nine million people. The division cares for approximately 9,000 patients who are classified as being retarded, in five state hospitals, institutions and schools. In addition we also are serving approximately 2,350 children under 21 years of age who have been excluded or excused from public schools largely due to the fact that they are said to have intelligence quotients of 50 or below.

The community class program for retarded youth which is under Ohio's revised code of 5125.01-.05 was placed in the Division of Mental Hygiene as a result of legislation passed in 1951.

May I take time to point out in accordance with Dr. Ginsberg's remark that the Division of Mental Hygiene is under a physician, that it is a medically controlled program, essentially to differentiate from a public school educational program. I join Dr. Ginsberg in saying that I feel that this is basically a medical problem.

To go on with Dr. Duty's remarks, it is my understanding that Ohio is the only state of about 26 states, which has such legislation placing the program in mental hygiene and not in education. Perhaps Ohio's plan for assisting parents who choose to keep their severely retarded children home and in the community may serve as a pattern for other states in the future, although we realize our program is unique at the present time.

For the most part the community program consists of group experiences or classes for 8 to 12 children inclusive, for four and a half to five hours a day for five days a week. The elapsed time includes lunch and rest periods which are considered as integral parts of the full training program. For each group of children there is a head teacher and sometimes an assistant teacher who may also be serving as a bus driver or a mother. Most of the classes start at 9:15 a.m. and let out by 2:00 p.m.

By law the administrative agent at the county level is the Welfare Director or the Cild Welfare Executive. Each administrator may choose within the framework of the rules and regulations whether his office will supervise a program or contract with another agency or group to administer the program in its entirety or in part. The past school year (1956-1957), there were 186 classes in the state. The division approved only 117. Ten percent of the classes were supervised by the child welfare board executives, four percent by the county welfare directors, 64% by the county councils for retarded children and 22% by the public schools. Each and every class was started on a wing and a prayer which means there were given individuals without capitol of any kind in the 55 of the 88 counties who thought it was time that the small segment of our population, parents and children included, should be recognized. This key individual has been able to rally around him or her, parents and interested persons who would not take no for an answer and work together in a positive manner. The probate judge or parent, the college professor, the welfare representative, a club woman, service club person, pediatrician, psychologist, social worker, minister, county nurse, educator and housewife, etc., have served as the spark in different counties for six years until there are now about 210 classes in 55 counties with additonal classes starting almost every other week.

I would like to emphasize that Ohio's community program for the severely retarded children has become a cooperative program which may be the secret of its success thus far. It is certainly a program which has caught his imagination, also that of many others and especially that of the members of the Ohio State Legislature.

The biannual budget has increased from $75,000 to $750,000. In four stations not a single class has closed after being once state approved. The state's share of the total cost is $200 per patient but if a similar individual were in one of our state institutions the cost to the state would be $1,050. I think that figure is a little low. In addition to the group experiences and classes we have also had two special clinics which are designed by intent to serve the retarded children and their parents.

Our latest community services for the families where retardation is present is a home visitation program which has been working exceptionally well in two counties. Instead of children coming to the teacher, the teacher, nurse or psychologist goes into the home and assists the parents in accepting the child and demonstrating various teaching methods. As a result of our present community programs for the retarded child, we have had a request for the past year and a half to consider having small combined day residential centers on a county, bi-county or tri-county basis rather than to continue building large institutions, which by their very nature, become quite impersonal. Perhaps you would like to hear comments made by a family after their child had been in a community group experience or class for one year.

"It has been a tremendous effort in our family.", that is quoting some parents. "Since he has ended training classes it is as if an overwhelming worry has been lifted from our lives, suddenly he is a school boy with his hour to leave and come home., his interest and his sister's interest have much more in common now. She looks with respect at his efforts in class as we do. It has meant a great deal to his sister to say he goes to school. A special school where they make the nicest things and have parties, rather than to always be at a loss when other playmates ask her, 'Why doesn't your brother go to school?', and it is necessary for her to go through that mentally retarded bit again. It has given him and me respite from each other, which he needed as well as I did. It is such a joy to get him ready for school and to see him come home so elated and proud. He is very eager to go to school every morning. School has had the effect of suddenly making our homelife normal. Our son has improved every year and fits into our life with no problems more serious than those of his normal sister".

I will not read the second experience, it goes much along the same line. To get down to the final paragraph of Dr. Duty's talk, the longer we work with community programs, the more we are inclined to feel that one of the major goals is improvement of the social climate and mental health of every member of the family.

The Division of Mental Hygiene will be glad to send you data and have you visit any phase of its community and institutional services for the retarded.

GOALS AND DIRECTIONS OF WISCONSIN'S PROGRAM FOR THE RETARDED

Leslie A. Osborn, M.D.

MEDICAL GOALS

Four hundred Mongoloid children have been born of mothers exposed to radiation by the bombing of Hiroshima. The danger that 'fall out' presents to present and future generations has been stressed by Nobel prize winner Dr. Linus Pauling.

Radiation experiments at Oak Ridge, Tennessee, are producing congenital anomalies suggestively like many that occur in humans. It has been found that spina bifida thus produced seems related to some growth-control factor from the spinal cord; the bones will resume growing in tissue culture under certain conditions.

Other forms of damage to the developing animal embryo and fetus are being used. Dr. Theodore Ingalls of Harvard uses temporary reduction of oxygen supply to one fetus of a litter in white mice and produces a variety of congenital anomalies.

Interest in the damage that can be done by viruses was aroused by Gregg's discovery in 1941 of the role that Rubella can, and often does, play in producing retardation, cataract and deafness in the first three months of human pregnancy.

It appears that the earliest days of human development are highly, but not fully, protected from damage. The stage of development at which damage occurs seems often more significant than the specific nature of the damaging agent. Very early damage is most serious, as cells injured are the "aulage" from which many other cells should develop to take their place in the fully-developed human being. Less of these precursor cells presumably plays havoc with the intended cellular architecture of the brain with resulting mental deficiency.

These significant medical facts have immediate importance to all of us. We have already seen that prevention works in cretinism and in congenital syphilis. Each of these observations suggests that we could be at the dawn of a new era of prevention. This could be significant to all prospective parents.

Relative prevention seems possible already in phenylpyruvic oligophrenia. Even with the defect in metabolism, development is not retarded if the phenylalanine which cannot be digested is kept very low in the diet.

Wonderful progress has been made in reducing infant mortality though still too many babies die. The new era of prevention could markedly reduce infant morbidity. This refers to ten times as large a group of young lives which are damaged in some way, before, during or soon after birth. In addition to the retarded, this group includes blind, deaf, cerebral palsied, epileptic and congenitally-malformed children. Add to these lost or damaged lives the ones due to abortion and miscarriage, and the figure (as estimated on a world-wide basis by a United Nations Report) even reaches one-third of all human conceptions in which something goes partially or totally wrong.

I have dwelt on this because medicine generally has scarcely faced the problem and is not in a position to do so on the scale needed. The clinical cases mostly are in rurally-located institutions, away from university and medical centers.

One of my first recommendations on coming to Wisconsin in 1950 was that a primarily medical colony be built in Madison, close to the University of Wisconsin

and its Medical School. The Board of Public Welfare immediately approved the proposal. It was presented in detail to the 1953 Legislature. With the strong support of our parent groups headed by Mr. G. I. Wallace, who is with us today, it was authorized by unanimous vote of the 1953 Legislature. We have been in detailed planning since. The first units are under construction. Further details may be obtained from Mr. Harvey A. Stenvens, its Superintendent, from me, or from the report of our program which has just been mailed to the Commissioner or Director of each state's program. Central colony's Medical Director is on assignment for a year, visiting 36 states to gather the latest ideas available. It will have specialized surgical facilities.

The challenge of the ever increasing number of low-grade cases is one of best possible medical and nursing care combined with medical research and education, aiming toward prevention.

THE RETARDED CHILD IN THE FAMILY

The whole pattern of family life is changed by the fact of retardation. The child may not become self-sufficient as soon--if at all. He may still have a dependency when his parents can no longer care for him. The parents must rethink their whole attitude to parenthood--often while their feelings are confused and the actual medical conditon of their child has not been clearly established or explained to them.

For the sake of child and parents, the facts must be learned as early and accurately as possible. Their feelings and their altered role must be worked out, with the help of professional persons such as doctors and clergy and of parent groups, who can often help a lot. A realistic, well thought-out plan for the child in due relation to the total family situation is important as soon as possible.

We plan to add to present resources a developmental diagnosis service in our Central Colony, which later may be extended elsewhere in the state. Basic medical, neurological, measurement, psychological, laboratory data, etc. will be gathered, using photographic methods like Gesell's and applying the Wetzel Grid as Dr. Walker had done at Polk, Pennsylvania. Then data will be started on in-patient study when retardation is suspected. Regular out-patient followups will build developmental records. The growth curves for different types will vary. The accumulated data will build up facts and experiences against which new cases can be checked. Thorough study, accurate diagnosis and prediction and skilled guidance will help minimize the uncertainty, "shopping around" and resistance to realistic acceptance of and planning for the child. (Such data on early development may help in determining suitability of very young children for adoption.)

In severest grades, the home may not be able to double as a hospital, especially in hydrocephalics and others when care is constant and technical. Some, like Mongoloids, may best be cared for at home for the first few years and then be given the benefit of special, skilled teaching in a training school. Wisconsin has not had any age limits but has accepted children on a basis of need, within limits of capacity. The pressure for admission of such low-grade dependent cases is great and growing. They now are 45% of Southern Colony's population and we have waiting lists. The trend is similar at Northern Colony.

THE HIGH-GRADE RETARDED

Here the trend is away from colony care. Many of a type once committed never need institutionalization. The southern Colony has dropped from 43% to 17% such cases in a decade. Over a thousand have been returned to community living in this period.

Our schools and Department of Public Instruction, represented here by Mr. John Melcher, have increased special classes from forty in 1939 to some three hundred. Teacher shortage is the chief problem facing further growth of this program. School consolidation and transportation have brought special class to most such children in our state.

The high-grade cases coming to our colonies now usually have associated organic, epileptic, emotional or social problems. They are an important and different treatment, education and rehabilitation group.

DEPRIVATION RETARDATION AND PSEUDO RETARDATION

We feel that some children--perhaps many--formerly classed as familial may show a net I.Q. lower than the potential gross real ability I.Q. because of deprivation of needed affection or social and educational stimulation from parents who may be unable to help them for a variety of reasons. We need to study further the role of the "education that begins at birth" in these cases. Some of these come from big families in a tarpaper shack, which one of our judges calls "country slums". We have difficult problems in relation to these under-cultured, often migrant, subsistence-level families.

Anxiety in its various forms, from mild through neurotic to psychotic, can produce under-achievement. The low level of function may not be recognized as secondary. The emotional or socially disturbed child needs treatment before he can live up to his potential. We must press development of psychological and psychiatric services to recognize and treat them. We plan a special cottage for this group in our Central Colony, which is adjacent to Mendota State Hospital.

THE TWILIGHT ZONE

Dr. Thaddeus Krush has called I.Q. 70-90 "the no-man's land of child psychiatry". Not retarded but not average, they tend to be unhappy, misunderstood and all too often rejected and berated for not being able to perform way over their heads because other children can. They show up disproportionately in other mental haygiene and correctional programs. We are initiating a careful study of this group. Many of them find their way to our colonies, but do not truly belong there--or anywhere else, as yet.

OUR OLDEST INHABITANTS

The middle-grade group, as shown by Minnesota's study of 400 cases at Faribault State School from 1910 to 1950, outlines the biologically-limited low grades and does not have the placement potentials of the high grades. Medical advances have prolonged the lives of many, with better nutrition, immunizations, and treatment of respiratory infection. The institutional longevity figures for custodial

care are startling. Details are in the appendix of our circulated report.

From Northern Colony, established 1897, our figures show that some 7 in residence over 50 years; 23 over 40 years; 107 over 30 years; 230 over 20 years; 270 over 10 years and nearly half the 1800 patients there 5 years or longer. If one person had been receiving all the years of care which Wisconsin has given to its many cases in institutions now, that one would have been in the institution 168,000 years!

The first long-range goal here must, of course, be prevention. Second must come as much development as possible of the potentials that do exist. Often, passive care is given by well-intentioned families who know not how to encourage any self-sufficiency. Such cases may be committed grossly dependent in their 20's or 30's. Perhaps early life care with special schooling in a colony could lead to longer community living as adults. Under the leadership of Mr. Stevens, who was Superintendent of our Southern Colony from 1947 to 1955, we have seen that much can be done with this group. The new patient buildings and wonderful Educational-Rehabilitation Center opened last year have helped greatly. Mr. John Garstecki, Superintendent of Southern Colony, will be glad for any of you to plan to visit and see these facilities and programs.

The schooling of the high-grade group has long been well developed. For them, we are stressing social development, vocational training and later rehabilitation. This latter is in conjunction with our Department of Vocational and Adult Education, here represented by Miss Irene Dunn. A program of work placement and family care has been growing. Mr. Nelson, Superintendent of our Northern Colony, and Mrs. Mary Jane Clark, his chief social worker, have done fine work especially in relation to the rural parts of our state. They are here and will be glad to give details, which are important to the "longevity" problem but cannot be given here.

Mr. Harvey Stevens deserves prime credit for pioneering in the field of the "trainable" middle-grade group in our state. This work won national recognition and New Jersey took him in 1955 to head its new research unit at Bordentown--but he has come back home now to succeed Mr. J. Howard Murphy as Superintendent of Central Colony. Mr. Murphy died of cancer in December 1957.

Beginning in 1948, Mr. Stevens and his staff worked with the idea that mental deficiency is a negative concept. It stresses what the individual lacks or cannot do. They felt that the child was retarded--a "slow learner"--and sought patiently and skillfullly to cultivate what he has and can do. A little reflection tells us this is the sensible approach. After all, some people train monkeys, seals, crows, even lions and tigers. They have needed much patience (and courage too, as far as lions and tigers are concerned!). None of these lower animals has intelligence equal in many respects to that of a middle-grade retarded child.

We have ward after ward of patients with I.Q.'s of 25, 35 and 45 whose potentials for human relationship and self-care were not developed in years gone by. Many just sit. Many cannot dress or feed themselves. Many wet and soil. Southern Colony changes 7,000 diapers and 3,000 sheets a day. Passive custodial care requires lots of personal service!

In our "Activities for Daily Living" classes, we have 7 children with I.Q.'s under 20; 23 with I.Q.'s 20-30; 27 with I.Q.'s 30-40; above that they go into more advanced classes. We will train more as we get the teachers. The children have 1 and 1/2 hour classes in well-planned classrooms with toilets, wash basins and

nursery school like setups. Each teacher has four groups a day. The children learn to have fun, sing nursery rhymes, recognize their spoken and written first names, pick up their own soap and tooth brush, wash their faces, use the toilet. They learn to identify colors and common objects. They come into childlike affectional relation with people--a far cry from the isolation within themselves of the unhelped older group. The teachers help them develop manners, serve each other juice and crackers, speak some simple words according to ability.

After two to three years, these children have well-developed social habits. They are alert and bright. It is amazing to contrast such 6 and 7 year olds with the zombie-like patients of like I. Q. who just sit in custodial wards. The latter do not relate, need feeding and dressing, often wet and soil. We believe the future of these children is much brighter, even if some will remain perennial children in an institution. We are confident some will be helped to live outside the colony as their full potentials are developed and educated. What contact might Helen Keller have had if no one had reached in past her handicaps? We feel we must explore further the extent to which we can reach these children. The deficiency may have been ours as well as theirs.

We are fortunate in having Bethesda Lutheran Home in Watertown and St. Coletta's in Jefferson as two private schools which are giving devoted and skilled care and are working harmoniously with our schools and colonies.

As we develop the potentials of slower children, specific concrete training experiences in the colony must link through social service with the community. Scout camps, shopping trips, visits to "Braves" games, our school buses, swimming trips, chorus and music groups help make the colony a part of rather than apart from the community. Northern Colony is doing interesting educational work with its canteen. We stress the importance of religious activities. Supervised, paid work placements have been effective, earnings going to the patient's account.

Small groups help the activities. The old dormitory dayroom setup is still with us but has been modified by dividing each in half and so halving the group into two separate dayroom sections. Aides get a closer, more personal feeling from this.

Community education of middle grade groups is increasing. Our Milwaukee parent groups, adapting Mr. Stevens' work, developed trainable classes in Milwaukee and won the 1951 Lane Bryant National Award. Milwaukee Schools took over these privately started classes and the 1953 Legislature provided funds to help such classes, of which there are now 30 in the state.

High school age classes of special type have been very successful.

Vocational rehabilitation is strongly interested in work placements. We are deliberating on extension of family care and on sheltered workshop possibilities. We have many of our adult retarded--some 1800--on transfer from our colonies to our county hospitals. This is a system unique to Wisconsin.

Such a diversified program tells of the wonderfully generous support we have had from the public, our legislators, Governors, judges, our Board of Public Welfare, Department of Public Instruction and other state and private agencies. We feel that there are many aspects of this problem. Necessarily these came under different jurisdictions. Harmonious cooperation is vital to success and the parent groups should be given fullest credit for their contributions.

Lest it appear that all is serene north of the Illinois border (as we hope it is with our hosts south of it), I hasten to state we have our troubles--lots of them. Most pressing is the quantity problem that constantly threatens quality. It reminds

me of the dear old lady who asked why the Japanese were driving the Americans back in the Pacific early in World War II; weren't the Americans better soldiers? "Yes" replied the officer, "One American is as good as ten Japanese, but never meets less than 11 of them".

Our colonies are overcrowded. Their facilities and staffs are overtaxed greatly. Yet we have urgent waiting lists. The pressure mounts as our programs improve. We have no means of knowing what the real back log of cases in the community is. We are presently conducting an inventory of all state services, public and private, under Mrs. Janet Coye. We want to know what we have, and what would be involved in full-scale study of prevalence of retardation in our state.

Systematic grouping was considered essential to growth. The Central Colony will help group major medical problems. This will ease medical pressures now felt by the others, enabling them to focus more on social and educational programs.

The 700 beds now planned at Central Colony (ultimately to be 1000) will not be enough additon to meet the quantity factor. A fourth, regionally placed colony for the northeast, may be needed. We hope to keep our colonies from getting too big. The retarded need personal care in small numbers.

PROFESSIONAL PERSONNEL

An adequate supply of well-qualified personnel is vital to program growth. We believe education of the family doctor has been overlooked all too often. We have conducted regular clinics for students from our two medical schools, Marquette in Milwaukee and University of Wisconsin in Madison, at Southern Colony since 1953. We are seeking to develop courses for practitioners.

We have a good course for teachers of retarded at the University of Wisconsin, Milwaukee, but its enrollment is far too small for our needs. We have field placements for social workers and psychologists and trainee positions for both. We conduct activity aide institutes at Southern Colony. We stress in-service training for our aides. Each has two weeks' preparation before going on the wards.

Our whole mental hygiene program is a combined clinical-educational one under joint leadership. We are linking each of our colonies with an educational institution. The Central Colony will give a great impetus to education in medical fields. The practical field training in Northern and Southern Colonies is very promising. We must keep working to attract many more young people into these fields.

RESEARCH

Last, but not least comes Research. Our whole program was joined under a research professor to develop the clinical fields, prepare them for use as educational settings and then move on to the unknown. We are in an excellent position to bring major medical school and university resources in contact with problems to be solved. The promise of limiting disability through educational research already has yielded fruit, and much more is to come.

In the face of such promises from positive programs, the human and economic cost of custodial defeatism appears staggering and unthinkable. We know a lot can be done already and can be sure of further gains as our efforts intensify. It is up to us to see that the promise of the present finds fulfillment.

CURRENT CULTURAL AND PSYCHOLOGICAL RESEARCH IN MENTAL RETARDATION

Thomas Gladwin, Ph. D.

Community Services Branch
National Institute of Mental Health

I have recently been privileged to collaborate with Professor Seymour B. Sarason of the Department of Psychology of Yale University in a survey of research in the psychological and cultural aspects of mental subnormality. This survey was conducted for the National Association for Retarded Children, with primary support from grants from the National Institutes of Health. It was under the overall direction of Dr. Richard L. Masland, now Assistant Director of the National Institute of Neurological Diseases and Blindness. Dr. Masland conducted a similar survey of the biological aspects of the problem, a subject which will be discussed by the next speaker, Dr. Wright.

We had three principal purposes in conducting this survey. First, we wished to assess the present state of knowledge in the field: what we know and what we do not know. Second, we tried to define more clearly the research problems which exist: what we need to know, and what steps we might take to establish such knowledge. We also felt it necessary to consider those kinds of research we would be well advised to stop doing until we have a better understanding of fundamentals. A good example would be the widespread use of intelligence tests as research tools when we really know very little about what the test scores signify. Finally, we hoped that through our report and by other means we could stimulate many more of the best researchers in the country to become interested in the field. Since it is woefully clear that the mere magnitude of the problem and the human distress involved has not been a sufficient stimulus to research, we have emphasized the contribution the study of mental subnormality can make to the understanding of mental and intellectual process in general. In this we see a close parallel with the knowledge of normal personality which has been derived from the study of psychopathology.

I could not hope in the time available to us this afternoon to summarize all the various aspects of subnormality which appeared important to Dr. Sarason and me. Rather I would like to discuss the broad outline of the research problem as we see it at the conclusion of our survey, and then review briefly the major recommendations for the kinds of research which we feel would begin to shed some light on what I am sure you would all agree is a very obscure and confused subject.

At the heart of the confusion lies the definition of retardation or subnormality. We can all agree on those severly defective cases wherein organic damage or disorder is clear and the individual's intellectual inadequacy is obvious. But such cases comprise only a small fraction -- perhaps one eighth -- of that

three percent of the total population we glibly say are retarded. What of the rest? We think of subnormality as defined by the I.Q. But the survey of referred suspected cases of mental retardation in Onondaga County, New York, makes one wonder. You will remember this survey concerned itself entirely with persons under eighteen who had actually been referred by people or agencies as retarded. Of the cases in this survey on whom test scores were available, one quarter had I.Q.'s of 90 or over--in other words, they were labelled retarded even though their I.Q.'s were clearly in the normal range. We find a similar inconsistency if we look at academic advancement: In the Onondaga survey about one quarter of the school-age cases referred for retardation were in the grades in school appropriate to their age. These figures, and similar ones derived from earlier studies, are undoubtedly familiar to you. I mention them here only because they underscore so clearly the fact that people can be labelled retarded in spite of adequate performance in either of the activities most commonly accepted as true reflections of mental ability. This means that if we wish to do research on mental subnormality we cannot assume that persons so labelled by the community are necessarily mentally subnormal at all.

Another stumbling block for research lies in the well-known fact that referral rates for mental retardation rise steadily through the school years, and then with the end of the period of compulsory schooling drop off dramatically. Obviously all these adolescents do not die, although if it were possible to die of joy it is probable that many of them would do so once they had the school years behind them. Rather they merge into the general population and are no longer sufficiently handicapped by whatever mental inadequacy may exist to make them a problem to society or probably to themselves. This is borne out by the several studies in which persons diagnosed as retarded have been followed up after a period of years. All of these studies show that the majority of such persons perform adequately both occupationally and socially and have children most of whom are entirely normal. Some studies even show a rise in the intelligence test scores of the original subjects after they left school. In other words, in the majority of cases mental retardation is of social consequence only for the limited period of the school years.

If we put these facts together several things become clear. One is that, omitting the organic cases, we cannot do satisfactory research on mental retardation as it is usually defined, since this definition, whatever it may be, is variable, unreliable, and includes within it factors other than mental ability. Presumably we should confine our attention purely to mental ability and discard the community's fuzzy criteria for retardation. But then we must ask, ability to do what? To perform in school, or to perform in the broader setting of our society? The data just cited make it obvious that these require different kinds of abilities, and failure in one does not necessarily mean failure in the other.

Actually, of course, we must be concerned with both school and non-school performance, but it is of vital importance that we know which we are talking about at any one time. This afternoon I shall be discussing primarily the intellectual requirements for satisfactory school performance, because it is a failure to meet these requirements which generates the majority of cases indentified as mentally retarded. This does not mean that there are not fascinationg theoretical and research problems in the area of non-school intellectual processes, problems

which have scarcely been explored at all outside of very specific work in occupational placement. This is, furthermore, an area in which I am particularly interested as an anthropologist, because it permits comparisons with non-European societies, where formal schooling is generally a fairly recent foreign introduction, where the concept of intelligence is not given the tremendous emphasis which we give it, where intelligence tests are unheard of, and where, consequently, mental subnormality is of such small proportion that it is not even considered a problem. Discussion of this would, however, carry us too far afield and beyond the limits of our time.

In considering the mental abilities required for satisfactory school performance we must also consider that required for intelligence test performance. Present-day intelligence tests, and even performance tests, appear to be quite unreliable in predicting social and occupational adequacy outside of the school situation. This is not surprising, for the early work by Binet, Terman and others in standardizing the first intelligence tests, against which practically all later tests are standardized, used school performance as the primary standardizing criterion. In other words, insofar as they predict anything I.Q.'s predict only school performance, and in view of the manner of their construction we should not expect them to predict anything else. Over the years a folklore has grown up which tends to define mental ability in all contexts in terms of the I.Q., but from the research point of view it would be a great mistake to accept such a demonstrably false assumption.

The ability of intelligence tests to predict school performance, even in the sense of statistical probability rather than the individual case,must also be viewed as very limited. It might be better to say only that test results correlate reasonably well with school performance, in that they tap approximately the same abilities, and not to consider them predictive. A statement of this sort immediately raises the question of why we should use intelligence tests at all, since they will tell us only what we already know or can know by looking at the school record. With respect to mental retardation at least I feel this is a good question to ask, and I personally believe we would know much more and be able to do much more about retardation if so much effort had not been wasted through the years in trying to figure out the meaning of test results.

There is substantial evidence to support this point of view. In the first place, tests available for use with pre-school children clearly do not permit us to pick out those children who will later become retarded. As Kirk has pointed out, it is extremely difficult to find pre-school children who are not organically disabled who have test scores in the range we would consider retarded, even among those minority groups whom we know will later contribute substantially more than their share of school failures and low I.Q.'s. Kirk believes this may be due to a delayed effect of cultural factors, but I believe we must also raise the question whether many children are not already developing habits of thinking and problem solving not suited for later school work, but the tests do not pick this up yet.

These are the years when children are forever asking "Why?" If a child is later going to have to grapple with problems in arithmetic or science it appears to me that he will have a hard time developing the appropriate mental skills if the answer he regularly gets is, "Never mind why, just do it." as compared with the child who receives an explanation, or even help in figuring it out for himself.

To anticipate a little in our discussion, this may be a crucial period in the development of the ability to think in terms of reasons and basic principles instead of only rules and specific instructions--in other words, to think in abstractions and not just concretely and factually.

Once he is in school the child is quite likely to go through several grades before he is identified and referred as retarded. This is evident from the rapid rise throughout the school years in the prevalence rates of referred retardation. The bulk of such cases clearly fall in the higher age levels, indicating that many children were not referred until they were well along in school. For this school-age population we have evidence which points rather clearly to the inadequacy of tests, as well as of teacher evaluations, in predicting retardation until the later years of school. This evidence derives from a large number of studies in which intelligence tests have been administered to underprivileged and culturally marginal children in school--to the children, that is, who contribute most heavily to the retarded population. Quite consistently it has been found that the average I.Q. of these children gradually falls from normal or near-normal levels in the first and second grades to below-normal levels later on. The significance of this fact becomes apparent if we remember that the content and problems contained in intelligence tests become more difficult and complex with each successively higher age criterion level. Thus the disadvantaged child who is not yet failing his schoolwork in the early grades is also not failing his intelligence tests; later on when he starts failing his schoolwork he will probably also start failing his tests. At this late date it is doubtful that he can be brought back up in grade. It is for this reason that I said that intelligence tests reflect academic performance rather than predict it, and questioned the usefulness of testing with respect to mental retardation not involving organic pathology.

Let me summarize the discussion up to this point. First, it appears that the mental ability required to function adequately in society is somehow different than that required for adequate school performance. This is particularly true in the lower ranges where the individual's adequacy is likely to be in question. Second,the I.Q. reflects school ability, not social and occupational competence, and this discrepancy is again greater at lower levels. Finally, neither intelligence tests nor, often, the usual means of judging school performance are able to provide any assurance that the more moderate degrees of retardation will be detected until a child has been in school for several years, at which time it is not only frequently too late to return him to the regular curriculum before the end of compulsory schooling, but also too late to undertake a longitudinal study to determine how he became retarded in the first place.

How did we get ourselves into this frustrating situation? One factor has certainly been the belief, now happily disappearing, that mental subnormality is a single entity, an irremediable deficit which is presumably inherited. The assumption that subnormality is unchangeable diverted attention from a search for early environmental causes and early detection of their effects. Although most workers in the field have progressed far beyond this point of view, there are still a few geneticists who are trying to prove its validity by chasing I.Q.'s through family trees in the manner of Goddard's Kallikak study of forty six years ago. These misguided efforts are not merely a waste of time. Anything which serves to keep alive the false stereotype of general hereditary taint impeded understanding and damaged people.

Intelligence tests also make their contribution to the frustration of progress. In one respect their hindering effect is also diminishing, in that it is becoming increasingly widely recognized that the I.Q. is not constant over time, but may vary either upwards or downwards as a child develops. Belief in the constancy of the I.Q. is still widely held, however, especially among parents and other lay persons, and naturally interferes with efforts to study the change and development of intelligence.

But a far more severe stumbling block is created by intelligence tests, one which is not only not diminishing appreciably but is scarcely even being attacked. This lies in the fact that we really do not know what intelligence tests measure. The corollary to this is that we do not know, and are making little effort to find out, what intelligence is. In the last analysis intelligence is defined for practical purposes as being what intelligence tests measure. Since different tests will often produce different I.Q.'s we arrive at the absurd point of having different kinds of intelligence without knowing whether any difference really makes a difference, since we do not know what we are measuring. Yet we have been chasing our tails around in this circle for so long that we seem to take it for granted that this is a reasonable way to function.

The root of the difficulty lies in the fact that the selection of items for inclusion in intelligence or performance tests is not guided, except in a very general way, by any consistent theory or concept of intelligence. Instead an assortment of problems, tasks, questions, word lists, symbols and the like are assembled and then winnowed out by statistical means. This winnowing consists essentially in administering the preliminary version of the test to a number of children of representative ages, scoring the results, and then determining which subtests correlate best with the overall test score, and whether the overall score correlates with scores obtained by the same children on some already standard test such as the Stanford-Binet. Those items which do not correlate sufficiently closely are dropped or modified until satisfactory intercorrelations are obtained, and the test as a whole produces scores reasonably comparable to those obtained with the standard test used as a criterion. The whold process of statistical standardization is devoted to keeping the test tightly within the same old dreary circle. Since intelligence is defined as what the existing tests measure, and the new test is also supposed to measure intelligence, there is no choice but to cut and fit until correlation demonstrates that both are measuring the same thing--whatever that may be.

We need to make a new start, and a few psychologists are trying to do just this, primarily through the use of factor analysis procedures. We must look at the nature of the thinking process, at the way people learn to solve problems and to pidgeon-hole in their minds their experiences and perceptions. We must see what kinds of intellectual skills are needed and used in what kinds of situations. This is a big order, and it would be reasonable for persons concerned only with retardation to say, "We will use the tools we have, and when the psychologists produce better tools we will use them, but it is not our job to rebuild the whole field of psychological measurement from scratch." This point of view would be understandable, but I do not believe it can be justified. The field of mental retardation provides an opportunity almost as uniquely essential to the understanding of intellect as psychopathology does to the understanding of personality.

I would like to make some guesses as to what we might find out if we looked at abstract versus concrete thinking. By abstract I mean thinking in terms of principles of general application, and attacking problems by trying to pull out of a series of observations a solution based on the perception of regularities and relationships between these observations. By concrete I mean dealing only in terms of the immediate and specific characteristics of things, and attacking problems through the use of established simple rules. At a practical level the contrast might lie between the mechanic who diagnoses engine trouble by listening to the engine and tinkering with it, testing hypotheses in his mind and narrowing down the possibilities, and the other kind of mechanic who plugs in one connection after another from a test stand, replacing parts without any basis for believing the parts he is replacing is defective.

If we accept the abstract and the concrete as two major categories of thinking and problem-solving processes, although they grade into each other, we may look first at the school curriculum. In the first few years the content of learning is largely at the concrete level--facts and simple relationships. Those subjects which are clearly abstract in nature, such as arithmetic, are usually taught in terms of specific rules to be applied to each type of clearly recognizable operation, a procedure in abstraction which is reduced to concrete terms. Gradually, in the higher grades, the amount of actual abstract thinking required of students increases. "Thought problems" replace simple figure work in arithmetic, and this is followed by algebra. Science is taught in terms of laws and principles. Principles of grammar are introduced into the study of English, and so on. At about this time also the prevalence curves for mental retardation referrals rise most steeply.

A roughly parallel change takes place in the kinds of tasks required in intelligence tests for the higher age levels. Naming objects, recognition, simple mazes and the like give way to more abstruse analogies and similarities, vocabularies containing words whose very use involves the ability to generalize in abstraction, and a variety of problems requiring reasoning and logic.

What happens, then, to the child we have mentioned before, perhaps from a lower-class minority group home, who asks "Why?" and is told "Never mind why, just do it"? He has never been encouraged to think things out for himself, and if his efforts to do so have interfered with his household tasks or obedience he may often have been punished instead. He can probably handle the relatively concrete curriculum of the first grade or two well enough to get by. Some of his tasks require reasoning and he often fails these, but there are not enough of them to bring his average down to a failing grade. His more fortunate fellows can handle the reasoning problems as well as the concrete ones; they not only get better grades, but their ability to think abstractly is also developed in the process. As abstract content becomes more and more important in higher grades the fortunate child develops his skills sufficiently to cope with it, but the child who was always working at a concrete level flounders and becomes discouraged and often hostile. There is no longer enough that is factual and specific to provide a passing average on the basis of such material alone. The fourth or fifth grade teacher refers him for examination, wondering meanwhile why the teachers in the earlier grades ever gave him a passing mark. The psychologist administers a test, requiring just as much abstract reasoning as the curriculum in school, the child gets a low score, everyone shakes his head sadly, and the child

is labelled retarded and put in a special class. There he goes back to concrete tasks and learning, but with a label of retardation attached to him.

How much better it would have been for the child had there been available a test, specifically designed to measure the ability to think abstractly, which he could have taken on entering kindergarten or the first grade. If he could have had special training at that time he might well have been able thereafter to stay in his grade without further help. Such a test would also, hopefully, make it possible to identify those children, who have a high likelihood of being judged retarded later, at an early enough time so that we could study the conditions of home and social experience which were contributing to their concrete mental development. We would learn much we do not now know about subcultural mental retardation, and know much better how to advise parents as to the way they should instruct their children.

A test of this sort cannot be constructed overnight. We have to know much more than we now do about intellectual process even to be sure that the abstract-concrete or any other dimension is the crucial one to measure. Then we have to devise means of measuring it which will have validity and some predictive value, again a major task, although one which flows logically from the study of intellectual process. Some studies have been undertaken which would lead in this direction, but many more people will have to become interested in this approach before we will really begin to move out beyond the vicious circle of intertwined curriculum and test content.

So much for school. How about extracurricular activities, and adequacy in later life? We know practically nothing of the intellectual requirements for performance in these spheres, except that they are different than those required for school. We do know, from a variety of ingenious studies and from the monumental work done with the records of World War II draftees, that standard intelligence tests are a most inadequate measure of the ability to get along in the majority of non-school situations. Yet this is a matter of great importance. Since at least one of the functions of any school system must be to prepare its students for life after school, this information would be of great value in curriculum development not only for special classes but for regular courses of instruction. It should be of great help in vocational placement and rehabilitation, for social agencies concerned with the potential adequacy of their clients, and in many other ways.

A major barrier to undertaking research on the intellectual factors involved in fulfilling occupational, social, and academic roles in our society is the obviously great complexity of the subject. J.P. Guilford at the University of Southern California is one of the very few people who has attempted, through special tests and factor analysis, to study the nature of intellectual processes. As of his last report on his work he had, he felt, identified forty separate factors in intelligence and was reasonably sure that his list was not yet complete. When his years of work are through it will then be necessary to begin the almost equally formidable task of getting his findings into useable form for clinical and other applications. If we contemplate the almost infinite array of specialized skills which are represented within the ranks of our vastly complicated society, this outcome is not surprising.

But there is one thing about Guilford's research which I have not mentioned:

his subjects for study are officer candidates for the U.S. Navy, a highly selected and presumably gifted and versatile group of men. I mention this fact because it should make clear the reason for my earlier statement that the mentally retarded can make a unique contribution to the study of intellectual processes in our society. Here we have a group of subjects whom we know are relatively incapable, for whatever reasons, of performing many of the intellectual tasks which can be handled by Guilford's officer candidates or indeed by any person fully adequate within his society. In this group far fewer intelligence factors are regularly or effectively used. Having identified these few factors we can go on to study the situations in which retarded individuals are able to perform adequately and those in which they fail, and those in which some succeed and others do not. In this way we can establish some baselines of minimal intellectual requirements in terms of meaningful factors, not just a global index such as the I.Q. With such baselines established we can build up our knowledge of more complex processes without losing sight of their relationship to specific kinds of culturally defined problems and challenges.

This research approach need not be confined to non-school contexts. By analyzing in terms of intellectual factors the successes and failures of a retarded child who is still "getting by" in the first grade we can learn much about the nature of the problems presented by existing school curricula, and then carry our study on up through the higher grades. Of course we do at present have the problem I have already mentioned of identifying at an early age those children who will not be labelled retarded until a few years later. However, there is a partial answer to this difficulty. There are a number of ethnic and other minority groups who we know consistently contribute far more than their proportional share to the retarded population, presumably because of the inappropriateness to the larger society of the learning experiences prescribed within their own subculture. By studying these children in the early school years we would at least have a greater likelihood of dealing with children who will be retarded later.

At the same time we gain in another way through the use of children from subcultural groups. It is reasonable to expect that children from one of these groups would differ appreciably in their intellectual processes from those in another, even though both might have a large proportion of school failures. By comparing the typical learning experiences in such cases we might obtain some real insights into the dynamics of mental retardation as we isolate each of the relevent factors.

In the process of this discussion I have touched on threee of the major research recommendations with which Dr. Sarason and I concluded our survey report. These were concerned with the need for studying the intellectual processes which go together to make up intelligence, for studying the nature of problem solving in non-test situations and its relationship to test performance, and for studying the cultural and subcultural factors which contribute to intellectual adequacy or inadequacy. The work on World War II draftees by Ginzberg and his associates has clearly demonstrated the tremendous importance of cultural factors in causing mental retardation.

I would like to conclude now by mentioning only briefly a few of the other recommendations we made in our report. One of these stresses the importance of making longitudinal studies of the development of severely as well as moderately retarded children, stressing the emotional as well as the intellectual aspects.

Everyone agrees that a family with a retarded child has a problem, but we really know very little about the effect of this problem on the parents and siblings, or how this effect is reflected back in the perceptions and experience and development of the retarded child himself.

Another recommendation is that more attention be given to the possible effects of differences in temperament between parents and their children. This is an extremely difficult area in which to do research because there are involved so many factors we are not yet equipped to measure or even to identify. However, some studies of autism and behavior problems have provided intriguing suggestions of blockage and interference in intellectual as well as emotional development in children as a result of a lack of fit between the personalities of parent and child. It is very possible that this kind of discrepancy can be of importance in many cases of retardation which are not associated with behavior disturbances sufficiently severe to result in diagnoses of autism or even character disorder.

Lastly, we pointed out the relatively high incidence of psychosis which develops among the institutionalized mentally defective. Studies of institutional populations from this viewpoint would not only contribute to our understanding of the emotional aspects of severe mental subnormality and of institutionalization, but would also provide a better opportunity for clinical studies of psychosis before as well as after the onset of the illness. There are available practically no studies of psychotics conducted before the psychosis was apparent, so our knowledge of the early stages is derived almost entirely after the fact. This is a serious handicap to the study of the problem, and one which might be partially alleviated were more attention paid to the psychiatric study of institutionalized defectives.

I would like to close with the personal observation that I see a tremendous research challenge in the field of mental subnormality. Dr. Sarason almost had to hit me over the head to get me into this survey, on the basis of our earlier collaboration on an entirely different subject. I could see no research potential in a field so dull and so hopeless I emerged two years later with a sense of real eagerness and excitement over both the importance and the possibilities of this research. I hope I have been able to communicate a little of my excitement.

CURRENT RESEARCH IN MENTAL RETARDATION - BIOLOGICAL

Stanley W. Wright, M.D.

I am eternally grateful to Dr. Thomas Gladwin for presenting his report because I think he has really brought up some of the pertinent points about this field of cultural and psychological factors in mental deficiency. I can highly recommend the complete report of Dr. Seymour B. Sarason and Dr. Gladwin which appeared in the last issue of 'Genetic Psychology Monographs'. It was a very nice critical review and appraisal of this problem. Dr. Richard Masland has also written a report on the medical aspects of this problem and I highly recommend this also. Dr. Masland has covered the prenatal, the perinatal and postnatal causes of mental retardation from the standpoint of genetic and environmental factors. He has also discussed the neuropathology of the mental defect as well as regeneration of the central nervous system. His appendices contain summaries of the medical research that is being carried out within various state hospitals and medical centers. I think that both of these reports should be in the hands of every physician who is concerned with problems of mental deficiency and I think that both of these reports are going to serve as guideposts to future research in this area.

Because of my familiarity with certain aspects of mental defect, and I shall continue to use this term mental defect throughout, although I am not really sure that there is this difference in mental retardation and mental defect, I will say mental defect. Because of my familiarity with mental defect problems and because most of the work we are carrying out is related to these problems, I will confine my remarks to a discussion of one, the epidemiology of mental defect and two, biochemical dysfunction as a cause of mental defect.

All of these studies that I am reporting have been carried out in cooperation with the National Institutes of Mental Health, the University of California, Medical Center of Los Angeles and the California Institute of Technology.

With regard to the epidemiology of mental defect, I would like to rephrase this term and say the natural history of mental defect. I think this is a very important concept because if we looked at many of the diseases that we cannot only treat but prevent, such as diabetes, poliomyelitis, rheumatic fever, etc., perhaps we are not quite as effective in all of them, but at any rate before we really institute good measures of therapy or prevention we had to first understand the natural history of these diseases.

I think we are woefully lacking in data on the natural history of mental defect. We have made some preliminary in-roads into this problem and what we call a population movement study. In just a moment I will show a slide of some of this preliminary data. This is taken from a study of 722 first admissions to Pacific State Hospital during the years 1948 to 1952. The only variable I will present here is the variable of diagnosis.

FIRST SLIDE:

This represents a graphical portrayal of the 722 admissions in terms of diagnosis and in terms of these three variables as to whether they were retained in the hospital, whether they were released alive, or died. Along the ordinate we have percentage.

Along the abscissa we have the years followup. The curves represent then a cumulative percentage over a four year period. I would like not to discuss all the curves on these charts because it gets too involved. Just simply point out the curves for two groups of patients, one the so-called familial and undifferentiated mental defect and the other the developmental cranial anomalies such as microcephaly, hydrocephaly and mongolism.

If we look first at those released alive, we notice that in the familial and undifferentiated mental defect, at the end of a four year period, about 60% of these patients have been released alive from the hospital. By released alive, I mean direct discharge, indefinite home leave, family care, foster homes, work leaves. etc. The intention is that the patient does not return to the hospital, but we do know a certain percentage have returned. We do not have the data on that. It is interesting that over a four year period some 60% of these patients got out of the hospital. We look at the dying in the hospital and find a very small percentage of these two groups died, and if we look at the retained percentage we find that at the end of four years about 40% were still in the hospital.

If we turn our attention to the other two groups of children, we look at the developmental cranial anomalies and mongolism. We find at the end of four years, only 10% got out of the hospital and unfortunately the death rate in this group of children was very high. About 20% at the end of one year and about 30% accumulative at the end of four years had died.

Over here you will see some 60% were retained in the hospital. I am not going to present the data which relates to age and I. Q. except to say that in the young children 0 to 4 years of age, when first admitted, their curves are very much like those for mongolism and developmental cranial anomalies. When you plot I. Q. on these charts you find that where the I. Q. is less than 19, the curves are very much like those for mongolism and developmental cranial anomalies. These are preliminary data, I know, and we are attempting to extend these to include some 4,000 admissions to the hospital. We are going to study these 4,000 admissions, we have already started them, in terms of behavioral, cultural, social and physical factors which effect admission to the hospital, retainment in the hospital, death in the hospital or release from the hospital. This should be quite a long term of study but we feel that this will give us considerable information on the histroy of mental retardation in the hospital.

I would like to project this into the time before they are admitted and also into the time after they are released from the hospital, but I think this type data will be very important from the standpoint of hospital training programs, research programs, administration, etc. Similar types of study can be done on certain examples of mental defect, the mongoloids, for example.

We have some excellent text books and a great many articles written on mongolism but they are cross sectional studies. They just simply cut across one particular segment, age segment, biochemical segment or whatever it is. I think that some day somebody could develop a very fine project on the natural history of mongolism and you could begin first with the entire family and then this could be narrowed down to the pregnancy history of the mother and then the pregnancy that produced the mongoloid child. Then what happened to the child after birth, was he alive at the end of the week, at the end of a year, or what was his medical problems, congenital anomalies, etc.

I think this would provide fine data on the natural history of mongolism and might eventually lead to better clues than we have today as to the etiology of mongolism. I should remind you that I do not think we know any more about the etiology of mongolism today than we did when Dr. Langdon Down first described the disease in 1866.

The second aspect of our studies I would like to discuss are biochemical disorders as a cause of mental dysfunction. Under present knowledge I doubt that 3% of the known cases of mental defect are due to a known biochemical disorder. It is a very tiny number, but yet about some of these diseases, we have considerable amount of information and we appear to be describing new biochemical syndromes that are associated with mental defect all the time. Just in the last January 24 issue of 'Lancet", Dr. Charles Dent from England, pointed out a new type of mental defect associated with the specific type of aminoacids in the urine. The interesting thing about many of these biochemical defects is that they appear to be genetic in origin and if we carry this on a little farther we find that it is genetically determined enzymatic abnormality. So there is deviant metabolism of a specific nutrient or substrate.

If these are diseases of enzymes, then presumably they are all protein diseases, though we would like to suggest some term such as 'enzymatic mental defect', may be appropriate to this group of disorders. I do not know if this is appropriate now. I am going to show about five or six slides. On them I have listed the diseases and biochemical disorders as they are associated with diseases of protein, carbohydrate, lipid metabolism, disorders of hormones, syntheses and a group of miscellaneous disorders. I would like to use the slides as a background to point out the type of research we are interested in and also the type of research that needs to be carried out.

FIRST SLIDE:

This is a summary of those mental defects that are associated with disorders of protein metabolism. Each slide is the same in that the clinical findings, the metabolic abnormalities and genetic pattern is presented. I am sure you are all familiar with the phenylketonuric child. Each disease is "H" disease or a disorder described in England in which there is a pellagra-like rash, cerebellar ataxia, presumably a disorder in tryptophane metabolism with the excretion of large amounts of indole compounds in the urine. Wilson's disease or hepalotenticular degeneration probably very rarely gets into a state hospital, however, they will show in the late stages, mental deterioration. The disorder is in some way associated with copper metabolism, although it may only be a secondary effect.

One thing interesting about this slide, that we have carried out a little further, is that as you look at the clinical findings for these three diseases you see that in Wilson's disease and in "H" disease there are some characteristic clinical findings. There is the Kayser-Fleisher ring or the pigmented ring at the limbus of the cornea. There is this pellagra-like rash in the cerebellar ataxia. These diseases could probably be diagnosed on clinical appearance alone but the phenylketonuric cannot be diagnosed on appearance alone. I have seen too many children, who are blond and blue eyed and give every appearance of being phenylketonuric, and they are not. Therefore, we were interested in how you would go about picking out a group of children in whom there was every likelihood that a biochemical abnormality might

be present, but who also present no striking clinical signs. When we look at the genetic pattern over here we see that there is a recessive pattern of inheritance in each of these diseases. In other words, the parents are carriers for heterozygous and the child is a homozygous. It is a single gene type of disorder. Then it occured to us that perhaps if we wanted to get a group of children together, when the likelihood was high that there was a genetic disorder with a biochemical manifestation, then perhaps we could get a group of defective siblings, or two or more defective children who had occured in the same family. We have initiated this type of study and on the next slide, with apologies to Dr. Gladwin, I would like to present the I. Q.s of these patients.

I am sorry we had no other way of portraying these patients in some semblence of a curve, so we simply plotted the I. Q.s of the defective siblings in the family. There are some 70 or 75 families represented here. Of what known recessive disorders stand out, there are four instances of phenylketonuria which is a recessive disorder. There were four families in whom at least two children had phenylketonuria. There is also a family in which there are several members with Tay-Sachs disease, and a family in which there is gargoylism. There are some other miscellaneous disorders including microcephaly and microcephaly with spastic paraplegia, which is suspected to be recessive.

In examining all these patients, there are some 15 families in whom it does appear that there is a difinite organic neurological deficit and in whom there is considerable similarity between the affected siblings.

There is 16 pairs of twins in this group. We think this is a good clinical group and I would like to say that this is the type of study that could be carried out in state hospitals because any hospital has the same amount of defective siblings that we have. Anyone who does this type of study can come up with some very interesting clinical information and isolate certain patients who deserve further study.

As to what biochemical tests we are going to perform on this group, this will be apparent as we discuss the remaining slides.

Out of these 75 families we have 25 families where the mother or father, or both, were in an institution for the mentally ill or defective. I cannot tell you the interpretation of that, but I am sure people can interpret it in various ways. We would like to think that perhaps these parents represent a heterozygous state and that the child represents a homozygous state. I am obviously biasing all my presentation here toward the hereditary or the genetic aspects of this problem. The last thing I would want to say is that these are all genetic in origin. I know very well they are not. Some of them are birth, environment, sub-cultural, polygenic, or multifactorial inheritance, etc. All we are saying is we are trying to get together a group in whom we feel there is a good likelihood of inherited type disorder. Everything we say and do, we interpret in this light.

Back to the slide of disorders of protein. There is an interesting aspect that the clinical findings on phenylketonuria and "H" disease, it is not mentioned here, but it is concerned with the behavior pattern in these children. We look at some of these phenylketonuria children, I do not say all, but certain numbers of them, and they present a very bizarre type behavior. They show withdrawal reaction, fright reaction, extreme negativeism, if they speak they show perseveration, echolalia and also catatonic-like posturing and they give every impression of being a psychotic

type individual. In 'H' disease, which was first described in England in 1956 by Dent and his workers, along about 1950 or 1952 there was an article in English literature which was entitled "A Case of Childhood Pellagra with Psychosis". This was a psychotic child with pellagra. He did not respond to the administration of nicotinamen. For one thing pellagra is extremely rare, if not unknown in England, and they were quite unable to figure this out except as a case of pellagra.

After this report was presented in 1956 by Dent, they went back to this patient and tested his urine and found that he had aminoacidura indolerivitives in his urine and is pretty obvious that the patient had this disease.

The association of the psychotic like illness with pellagra is very interesting. Actually in true pellegra it is my understanding that bizarre behavior patterns are quite common. In these two disorders we have some indication that perhaps there is a relationship between mental illness and mental defect. In phenylketonuria we have an increase in output of certain phenol compounds in the urine and we are presently looking into this problem of the excretion of phenolic derivitives in the urine of psychotic individuals.

In "H" disease, it is a disorder of tryptophane and I think everyone here is aware of the role of tryptophane in certain neurophysiological processes. We are going to also look into this problem of the secretion of indole derivitives in the urine of psychotic individuals with mental defects.

One other aspect of these diseases that we have been interested in is the abnormality and heterozygote in phenylketonuria. Dr. Shaw, here in Chicago, is the first one to demonstrate that if you took the parent of a phenylketonuric and gave him some phenylalanine, he did not metabolize the phenylalanine as well as a normal person. We have been able to confirm and duplicate Dr. Shaw's study and also extend this. We have the idea, not original to us, that perhaps in mental defect, you might have multiple heterozygosity for certain disorders. Such that a mental defect might be heterozygous for phenylketonuria as well as for other metabolic disorders. Perhaps the combination or the summation of these genetic subnormalities might result in mental deficiency, therefore, we did phenylalanine tests on a large number of non-phenylketonuric defectives and we found they are all perfectly normal.

We have extended these studies now into a group of mentally ill patients at the Norwalk Metropolitan State Hospital and on the basis of the first few tests there seems to be several individuals who do not metabolize phenylalanine particularly well. However, beyond saying this, I would not go any further. I think we will simply have to repeat the studies on these individuals. We also have some studies going on, not on copper, but on trace metals within the brain tissues.

SECOND SLIDE:

These summarize the mental defects with disorders of carbohydrate metabolism. Considerable attention has been given to this disorder. Galactosemia which appears in the newborn infant is characterized by the inability to utilize the monosaccharide galactose, galactose being present in milk in large quantities. As far as I know, there is only one patient with galactosemia in the state hospital here in Illinois. He was diagnosed by the fact that a younger sibling developed galactosemia as diagnosed by Dr. Donnell in Children's Hospital in Los Angeles. He contacted the people here about this, and this older sibling also was found to have galactosemia, mild in character, who escaped detection in infancy and is now in the state hospital.

We took a group of 42 mentally defective patients who had cateracts, in the Pacific State Hospital, and we did galactose tolerance tests on them, as well as a group of controls. No differences were found in the cataract patients and the controls. However, we thought since we used oral galactose, we may try to repeat these tests using an intravenous galactose tolerence test.

Idiopathic hypoglycemia is probably a rare cause. By the time these patients get to the state hospital, the blood sugar may have been returned to normal. The seizures may have ceased, although they are left severely retarded.

Sucrosuria is probably very rare, there are only a few reports on this. Fructosuria has been described in association with mental defect. Looking at galactosemia, sucrosuria and fructosuria, it suggests that if you were to screen a number of these patients' urines for the presence of monosaccharides, such as these sugars, it might be very rewarding. We plan to do this in our group of defective siblings.

Gargoylism can be diagnosed clinically by the characteristic facial features, the disorder of the mucopolysaccharides, which are probably related in some way to connective tissue. Increased amounts of these polysaccharides are found in the urine. This is an interesting disorder in that it may be inherited in two fashions. One, it may be recessive or it may be sex-linked. In the sex-link form, the corneal infilltration is absent. Why we should have two types of inheritance in a disorder which appears clinically very much alike, I cannot tell you.

THIRD SLIDE:

I will not discuss the mental defects associated with lipid metabolism except to say the lipids are an extremely complex and difficult group of substance to work with. We have not done anything in this field. I have listed three distinct disorders, there is considerable overlapping in the diseases and actually there are disorders which are in between, in which lipid is still not well characterized. There may be some clinical overlap as well as biochemical overlap in these disorders.

FOURTH SLIDE:

These are mental defects associated with disorders of hormone synthesis. This is in particular relationship to thyroid disease. The most common type of thyroid disease is a so-called athyreotic or non-endemic cretinism. This is the child who has no thyroid gland and is a cretin as a result. These patients have a congenital absence of thyroid tissue. They show no ability to take up radioactive iodide I 131 and they are athyreotic. It has become apparent that some of these patients who are not athyreotic, may develp goiters or if given adequate thyroid therapy at the onset of their problem, a goiter may never develop, but if you do I 131 uptakes in these patients, you find that their I 131 uptake is not decreased but rather it is normal.

As time has gone on we have found that there are so-called familial goiterous cretins of which at least three types have been described clinically, these patients all appear alike. They all show a normal I 131 uptake by the thyroid gland and in each of these a seperate disorder in hormone synthesis has been described. In one it is a failure to bind the inorganic iodine within the gland. In the second, although they will bind the inorganic iodine, they cannot couple the mono and diodotryosine, and in a third, they cannot assimilate hyroglobulin.

Dr. David Moser of Pacific State Hospital took some 30 patients, who were there

in the hospital, and took them off their thyroid for about three weeks, then performed I 131 uptakes on these patients. Three of the patients had increased uptakes of I 131. The remainder showed no uptake and were presumably athyreotic cretins, however, of the three that did show a good uptake, two have goiters and the other is a result of consanguineous marriage and it does appear that there are three patients there who have some disorder in synthesis of the thyroid hormone. He is conducting further studies on these.

FIFTH SLIDE:

On the last slide are disorders of possible metabolic origin and these are extremely rare disorders. When I say rare, as far as I know, that no one has ever looked for them in the State hospitals. They are generally described in the pediatiric units of large medical centers, and as far as I know no one has conducted a survey in any state hospital to see how many of these are actually present.

The idiopathic hypercalcemia is characterized by severe degree of mental defect, hypercalcemia, metastatic calcification. These are cerebro-ocular-renal disorders which arise mainly by cataracts, glaucoma and by aminoaciduria. The diabetogenic diabetes insipidus is a type of diabetes insipidus that does not respond to pitressin. This maple sugar urine disorder is an extremely rare disorder but it is picked up by a characteristic of maple sugar in the urine. The congenital non-hemolytic jaundice with kernicterus is also extremely rare. It will be picked up by the fact that the child is constantly jaundiced.

I would like to point out that in two of these disorders we have aminoaciduria in the cerebro-ocular-renal disorder and in this maple sugar urine disease. If you think back in phenylketonuria, there is an aminoaciduria with increased output of phenylalanine. In the 'H' disease there was aminoaciduria hepatolenticular degeneration. In Wilson's disease, aminoaciduria and in galactosemia there is aminoaciduria. Therefore, a screening of urines for amino acids could be a very fruitful approach to picking up many of these problems.

Actually I am not sure but that if a hospital were faced with a problem of whether to buy an Electroencephalograph machine or some chromatographic equipment, I think they would be better off with chromatographic equipment. I think they would make a lot more headway with it. This is not to criticise the electroencephalograph.

It is also worthwhile pointing out that in these three disorders here, there is involvement of the kidney so that just the careful examination of the urine for specific gravity, acidity, alkalinity, etc., may often times give a lead to a patient's problem.

Last we have mongolism. I think there is a genetic element involved in mongolism. If there is, then there must be some biochemical manifestation of the genetic problem. The reason I believe there may be a genetic factor is gathered from the study of twins, from studies on family members on mongoloids, and from the reproductive histories of mongoloid mothers. The biochemical abnormality, if there is one, has not been very well characterized today, although, there is an increase in one fraction of the serum lipoprotein, an increase in this beta-aminoiso-butyric acid has been described, and this work needs to be repeated.

Minor abnormalities in total proteins have also been described. One of the interesting things about the mongoloid is its increased frequency of leukemia. Leukemia is apparently increased three to four times in the mongoloid over the normal. The leukemia can be congenital in origin, occuring at birth or within the early infancy.

It may be of a myeloblastic or lymphatic type. The relationship between the mongolism and leukemia is certainly not established. We carried out some studies last year on alkaline and phosphatase activity of the white cells in the mongoloids and in non-mongoloids and mental defectives. We also studied rebosenucleic acid in the cells. We could find no differences between the two groups. More careful biochemical measurements of these compounds might be of interest.

One thing about the mongoloid is that they have specific malformations involving the heart and intestinal tract. However, specific malformations of the brain are rarely described, but rather, a non-specific type of malformation. A neuropathologist for the California State Hospitals has pointed out that Alzheimers disease is much more common in the mongoloid. Alzheimers disease is interpreted as aging of the central nervous system, it is manifested pathologically by senile plaque formation in the brain, neurofibrillary changes and cell atrophy.

In the mongoloids that we have dying between the ages of 30 and 60 years, I think we have found these changes in some 60% or 70% of the patients. In a control group of non-mongoloid defectives, we find these same changes in some 3% to 5%, so that it does appear mongoloids have a definite predisposition of predilection to this type 'aging', and I use the word aging in quotes because no one knows what the changes really represent. Nevertheless, it certainly represents a future field for research.

There are other specific disorders which are genetic in origin and certainly need further work on. These include the neoplastic disorders, neurofibromatosis, hemangiomatosis, tuberous sclerosis, the demyelinating diseases, e.g., Schilder's disease, ectodermal defects, such as Rud's syndrone and chondrodystrophies, achondroplasia, Morquio's disease, etc.

There are also large groups of patients who might think that a clinical approach, too, would prove extremely valuable. For example, patients with cataracts. Just in our little study I was amazed not only at the number of patients with cataracts, but the varying etiology of these. Patients with cerebellar ataxia deserve much more attention. Of the last two types of mental defects that Dr. Dent has described in England, both have been associated with cerebellar ataxia and aminoaciduria. The children who are dwarfed would form a very fine nucleus for further study. Those with craniostenoses, those who give evidence, or the parents say the child developed normally up to a certain age and then began to regress., etc.

I am afraid we all think we have to have mass spectrometers and fraction collectors and a whole slew of lab equipment before we can do any work. Nothing is further from the truth.

In summary, I have talked of two things. One, the epidimeology of mental defect and how important this is in our understanding of the natural history of mental defect. Mongoloids are a good example. I have also tried to review some biochemical disorders which are a cause of mental retardation and pointed out simple screening procedures that could be used to detect some of these. Even a straight clinical approach can be very fruitful. I do not know what this is all going to bring us to, but I have the idea that as time goes on the eventual results of these studies are going to be to show that mental illness and defect may be all part of the same biochemical disorder.

TABLE I

MENTAL DEFECTS WITH DISORDERS OF PROTEIN METABOLISM

Disease	Clinical Findings	Metabolic Abnormalities		Genetics	
		Primary	Secondary	Inheritance	Abnormality in Heterozygote
Phenylketonuria	Mental deficiency, blonde hair, blue eyes, fair skin, eczema, musty odor of urine	Absent phenylalanine hydroxylase activity	Incr. Serum pheylalanine, incr. urine phenylalanine and derivatives-pyruvic -lactic, -acetic acids.	Recessive	Decr. tolerance to ingestion of phenylalanine.
"H" Disease	Mental deterioration, pellegra-like rash, cerebellar ataxia, photosensitivity.	Tryptophane	Incr. urine tryptophane, indoleacetic, indoleacetylglutamine, and indican. Aminoaciduria	Recessive?	Unknown
Hepatolenticular degeneration	Mental deterioration, neurological signs, cirrhosis, pigmented ring at limbus of cornea	Decr. synthesis ceruloplasmin? Syntheses of protein with incr. affinity for copper	Decr. Serum ceruloplasmin and copper Incr. urine copper aminoaciduria. Excess deposition of copper in tissues.	Recessive	Unknown

NOTE: These tables are being published with the permission of the A M A Journal, Diseases of Children, and are taken from an article by the author which is soon to be published in this journal.

TABLE II

MENTAL DEFECTS WITH DISORDERS OF CARBOHYDRATE METABOLISM

		Metabolic Abnormalities		Genetics	
Disease	Clinical Findings	Primary	Secondary	Inheritance	Abnormality in Heterozygote
Galactosemia	Mental deficiency, jaundice, hepatomegaly, cataracts.	Absent phosphogalactose uridyl transferase activity. (PGal transferase)	Incr. serum galactose, Incr. urine galactose, aminoaciduria, Accumulation of galactose-1-PO4 in tissues.	Recessive?	Abnormal galactose tolerance test in one or both parents?
Idiopathic Hypoglycemia	Mental deficiency, "blank" spells, seizures	Unknown	Decr. blood glucose, Casein-leucine induced hypoglycemia.	Unknown	Abnormal epinephrine and insulin sensitivity tests in one parent
Sucrosuria	Mental defect, hiatus hernia	Unknown	Sucrosuria	Unknown	No studies
Gargoylism	Mental deficiency, coarse facial features, contractures hepatosplenomegaly, corneal infiltration, skeletal deformities	Mucopolysaccharides?	Incr. tissue polysaccharides, Incr. urine chondroitin sulphuric acid.	Recessive or sex-linked	Unknown

TABLE III

MENTAL DEFECTS WITH DISORDERS OF LIPID METABOLISM

Disease	Clinical Findings	Metabolic Abnormalities		Genetics	
		Primary	Secondary	Inheritance	Abnormality in Heterozygote
Infantile Amauroses	Mental Deterioration, severe neurological disturbances, "cherry red" spot in macula.	Gangliosides?	Incr. gangliosides in CNS	Recessive	Unknown
Niemann-Pick Disease	Mental deterioration hepatosplenomegaly, anemia	Sphingomyelin?	Incr. sphingomyelin in R.E. System, Niemann-Pick cells.	Recessive	Unknown
Gaucher's Disease (Infantile Form)	Mental deterioration, hepatosplenomegaly.	Cerebroside (Kerasin)?	Incr. cerebrosides in spleen. Gaucher cells.	Dominant?	Gaucher cells

TABLE IV

MENTAL DEFECTS WITH DISORDERS OF HORMONE SYNTHESIS (NON-ENDEMIC CRETINISM)

		Metabolic Abnormalities		Genetics	
Disease	Clinical Findings	Primary	Secondary	Inheritance	Abnormality in Heterozygote
Athyreotic non-endemic cretinism Non-endemic familial goitrous cretinism	Mental defect, retarded physical and skeletal growth	Congenital absence of thyroid tissure.	Decr. I 131 uptake	Unknown	Unknown
Type I	Mental defect, retarded physical and skeletal growth. Goiter.	Failure to bind inorganic iodine.	Incr. I 131 uptake	Recessive?	Unknown
Type II	As above	Failure to couple mono- and diiodo-tyrosine.	Incr. I 131 uptake, Incr. thyroidal secretion of iodide. Incr. thyroidal mono and diiodotyrosine. Decr. thyroxin.	Recessive?	Unknown
Type III	As above	Absent thyroid deiodinase activity.	Incr. serum and urine mono- and diiodotyrosine.	Recessive?	Partial failure to deiodinate I 131 labelled diiodotyrosine.

TABLE V
DISORDERS OF POSSIBLE METABOLIC ORIGIN

Disease	Clinical Findings	Metabolic Abnormalities		Genetics	
		Primary	Secondary	Inheritance	Abnormalities in Heterozygote
Idiopathic hypercalcemia of infancy	Mental deficiency, hypotonia, vomiting, hypertension, "elfin" facies.	Calcium ? impaired renal function.	Hypercalcemia, metastatic calcifications, azotemia,	?	No studies
Cerebro-ocular-renal disease	Mental deficiency, glaucoma, cataract, osteoporosis.	?	Metabolic acidosia, aminoaciduria, decr. urinary NH_3	?	Aminoaciduria?
Nephrogenic diabetes insipidus	Polydipsia, polyuria, dehydration, Mental deficiency in some patients	?	Hypotonic urine, pitressin resistance, hyperelectrolytemia.	Sex-linked	Polyuria, hypotonic urine in female carriers
Maple sugar urine disease	Neurological, mental deterioration, respiratory difficulties, opisthotonos. Urine odor of maple sugar.	?	Increased valine leucine, isoleucine levels in blood and urine.	Recessive?	Unknown
Congenital familial nonhemolytic jaundice with kernicterus	Mental deficiency, severe neurological signs of kernicterus	Failure to conjugate bilirubin to glucuronide form	Retention of unconjugated bilirubin.	Recessive?	Unknown
Mongolism	Mental deficiency, typical facies and physical characteristics.	?	Incr. serum lipoproteins & urinary beta-amino-isobutyric acid. Incr. frequency of leukemia & Alzheimer's disease	?	Incr. frequency of mongoloid

FUTURE ROLE OF THE INSTITUTION FOR MENTAL DEFECTIVES

Gale H. Walker, M. D.

We are to consider during this next half hour the role of the institution for the mental defective in the future. This is somewhat a challenging subject which could permit flight of fancy. At the same time it brings with it all the hazards associated with attempted prophecy. I could be safe as Christmas by attempting to describe for you institutions for the mental defectives one hundred years from now, and could feel secure that none listening would live long enough to see the predictions fail. If on the other hand I attempt to paint a word picture of the institution as it may be in the predictable future, then I am faced with considerable responsibility to pinpoint rather accurately and soundly my prognostications.

In this then, I am between two dangers, first, that I in this flight into the future become so absorbed with a sort of science fiction enthusiasm that I soar far beyond the stratosphere of our reasonable knowledge. Again I may become too much engrossed with the situations of the present that our projections into the future never become airborne at all.

It is essential in plotting a course to have at least two points of reference before being able to predict a probable path in the future. This we have in our understanding of the institutions today and these institutions as they have existed in the past. So it must be that we use the data available to us today and from the past to deduct the position of these institutions in the future. If we consider the institution today and compare with what it was in these years past we find that our institutions have not changed radically in structure, in philosophy, or in staffing pattern. In fact perhaps we have not really kept fully abreast of the changes which have occurred in the social, economic, and medical currents that touch upon these institutions. We may rightly ask ourselves what forces and factors we will find in the future effecting these institutions that will be different from the forces and factors that have existed in the past.

We must assume that life will continue much in the same pattern in our land that it has always followed. That we will continue to live in a Democracy in which to great degree the action of government will be predicated upon the will of the majority of the people. We must assume that the moods of the people will be expressed clearly in those areas affecting the majority. We can anticipate a pride in our past, a continuing desire for improvement in our mode of living and working, and a reluctance to accept needlessly the shackles of an increased tax burden. We can anticipate an awareness in the people of the needs of others, but with deep personal involvement only when the needs are either dramatically demonstrated or close to our doorstep.

Only two months ago, in January of this year, the Arkansas Children's Colony released some information collected by questionaires sent out during 1957 to institutions for mental defectives in this country. The tabulated replies represent reporting from sixty-nine institutions for mental defectives in forty-two states. Fifty seven of these institutions listed both patient load and waiting list. Although the reporting does not include some institutions known

personally to me, I feel the data is worth considering in this paper. Strangely enough the smallest institution listed, the Los Lunas Hospital & Training School of New Mexico with 163 patients reports the largest waiting list in proportion or 700 applicants waiting admission. Think of it! Over four applicants waiting for every bed in that institution.

Within the last ten years Arizona built an institution with a current population load of 455 patients. I know from personal conversations and communications with some of those responsible for the planning, that serious thought was given to developing a good school to meet modern needs. Now well within the decade in which the institution opened, it is faced with an acknowledged waiting list of four hundred applicants or only fifty-five persons less than already are in this school. I realize Arizona has in these last ten or fifteen years shown phenomenal population increase, but I would point out that Arizona is not the only state in which population has been increasing by leaps and bounds. Thus in our projection into the future we must ask, "By what token may we believe waiting lists will be eliminated in the future and that the mental defective child can have institutional treatment if he needs it when he needs it."

We can safely assume for our discussions today the degree of overcrowding in these schools for the mental defectives approximates at least 20% on a national average. Overcrowding comes about as an attempt to meet a large waiting list with insufficient facilities and tends to destroy the standard of patient care. Let us then now raise the question as to what indication exists that overcrowding and waiting lists will deminish in the future. I personally believe in the light of existing construction costs, tax loads, and similar factors that we have little reason to anticipate any great reduction in the bed space deficit nationally.

It is interesting to note, using again this Arkansas Children's Colony report, that the percapita daily cost in these institutions runs all the way from $1.80 listed for Beatrice State Home in Nebraska to a high of $7.56 for the Wayne County Training School in Michigan. One might raise objections that the Wayne County Training School by its selected patient population and program is not comparable to most schools in the country and this objection might be valid. In that case there are still two other institutions in the country listed in this same report with daily per capita costs in excess of $6.00. Thus we see the existing daily per capita cost with variation from lowest to highest of over 300%. We might well ask "What is the cost per capita needed for an institution of this type to fully meet the patient's maximum habilitation?" I feel we must make some consideration of cost inasmuch as these funds expended are primarily tax monies.

Tax monies have a manner of generally being spent in areas and for services which meet popular demands and interest. Tax monies are also for the most part obtained from individuals through taxes, fees, and licenses. The over-all payment to state and local government in this country averages $157.00 per year per man, woman, and child. The expenditures for state and local government in the states of Pennsylvania, New Jersey, and Delaware have exceeded income for each of the years from 1953. The expenditures for health and welfare in Pennsylvania, New Jersey, and Delaware in 1953 approximated 18% of the expenditure of government state and local of those three

states. (1) While not all this money went into the care of mental defectives, I believe at the same time we must raise the question as to what proportion of our tax funds can be, with logic, expended for such services, especially so when the expenditures must compete for support with other much more popular tax demands such as roads and new schools, to say nothing of national defense and rocket research.

We have seen popular waves of support swell state funds for mental health services and then be followed by a period of economy of some sort that nullified to great degree the gains that had been achieved. We delude ourselves if we anticipate the future institution to be free from financial problems for great lengths of time.

We have seen in the past and at the present time these institutions for the mental defectives are not only stone and brick but equally the reflection of the individuals who lead and staff them. We have seen some of these institutions grow, reach maturity, and wither when the degree of leadership required was not present. We have seen institutions slide back and then have regrowths of programs and standards when better leadership was available. We have seen these institutions constructed in some instances so ruggedly that their structure impeded alternations necessary to keeping pace with better programs. We have seen other institutions so lightly built that repairs and maintenance consumed large portions of their budget. Again we must anticipate these foibles will be with us in these future years that lie ahead.

We have assisted in the construction of institutions which often have become a type of monstrosity. Even at its best, good institutional living is abnormal and a poor substitute for a satisfactory type of home life. Even normal people are not constructed psychologically to identify with large groups of people. Poor institutional care risks the hazards encumbent to slave labor or living in a zoo or concentration camp.

We have seen during the past ten or fifteen years across this country a shift in the type of patient being received so that over half of those institutions listed in this Arkansas Children's Colony report have more severely retarded patients than high grade types. It is only natural that these declinging intelligence ratios within our institutions should continue in the future and become more pronounced. This is not only due to the siphoning off of higher grade defectives by community facilities able to give care but also equally due to changes in medical therapeutics that permitted survival of many children who a short time ago would have died at an early age. We have seen the Southbury Training School in Connecticut, created a bare two decades ago, as a training school for the higher grade defectives now approximating the pattern of intelligence scatter seen in other less specifically designed institutions. If the Southbury Training School with its superb facilities for training of the high grade mental defective must alter its type of program to meet the pressures for these lower grade patients, we must weigh carefully the premise of training schools in the future.

About one year ago at the Polk State School a survey of our waiting list revealed we had approximately 150 more awaiting admission who could not walk, nor feed themselves, nor care for their toilet needs than could walk and feed themselves and were toilet trained. In developing this data we excluded

from consideration all those applicants where there was equivocation concerning those abilities. Nor was this waiting list a residue of lower grade mentalities due to selective admissions. We find at Polk 9.35% Mongoloids in the institution against 13.3% Mongoloids pending admission; and 4.1% patients with associated cerebral palsy against 8.6% of those awaiting admission. These figures we believe have prognostic value in predicting trends in patient type that will influence the program of these institutions in the future.

While reluctant to inject a note which might cause interdisciplinary friction, yet I feel very sincerely the conditions incumbent upon these institutions in the future must require that the leadership of these institutions be medical leadership rather than any other discipline. The problem of care will necessitate increased medical resources, medical diagnosis, and medical treatment.

It has been my impression that the level of patient records in these institutions quite generally is rather poor, poor in some cases because insufficient effort was put forth to develop an adequate system of records, and poor in many cases because of the inadequacies of the system or systems of nomenclature we have attempted to use. I am certain the system of nomenclature as characterized by the etiological classification brought forth by the American Association on Mental Deficiency in 1957 was a distinct advance from the classification system promulgated by the same organization in 1946. As Past Chairman of the Committee that brought forth this classification published last year, I am certain that the etiological classification is not adequate to meet our needs very far into the future nor to meet the statistical needs in this field existing today. I am torn somewhat between an emotional desire to protect this baby I helped produce and an almost equal desire to renounce the baby completely. I am certain many institutions today would benefit if their records were brought to the level possible by complete application of this 1957 etiological classification scheme.

Although we did adjust our records at the Polk State School to the 1957 plan, I view with alarm attempting to change over within the next few years to a system of nomenclature and classification more closely based within the framework of the American Medical Association nomenclature system. Yet I acknowledge the necessity for such change over. Otherwise we will continue our double talk and continue to think and speak of mental deficiency as both a symptom complex and a disease entity.

It appears that we are attempting to day an increasing amount of care for the mental defective with too little attention being paid to a really understanding type of diagnosis. The increasing spread of attention to the mentally defective by the public school systems may be intensifying the situation much more widely than we recognize generally. In the public school special class the attempted care and training must be predicted upon intellectual functioning and education rather than upon etiological factors and is therefore an extension of symptomatic treatment without great consideration of causation.

If we speak of a Mongoloid as a mental defective we speak of him as a member of a heterogeneous group. If we speak of him as a mongoloid we speak of him as a peculiar type of mental defective. If we speak of him as congenital cerebral mal developed with mongolism we inject causative factors for the first time. How much more accurately does our thinking become, however if

we speak of him as "Mongoloid, due to unknown prenatal influence" or possibly "Mongoloid due to disorder of metabolism, growth or nutrition." If we could approach the mental defective within a scientific framework of thinking we might be able at last to think always of these persons in terms of what went wrong that made them as they are. We would, I believe, not only think more clearly, but would also enlist the thinking of some of those others in our disciplines who might have much to offer to our field if they could think in terms meaningful to them and to us without translation.

In a very similar manner we have become preoccupied collecting data in history taking concerning the mental defective that probably reflects our unconscious resentment of them rather than much scientific value in understanding them. At the same time we have ignored to a great degree many factors concerning their histories that might ultimately have value and use.

At the Polk State School we have for years asked questions and received answeres concerning items of family history such as "pauperism, insanity, criminal tendencies, extreme nervousness and blindness," and yet at the same time have only within the past two years begun to collect data concerning family history of diabetis. Frankly I am somewhat set upon to really define some of these things such as "extreme nervousness" and have a lot of doubts concerning the relationship of familial "extreme nervousness" to mental deficiency. I have more conviction concerning the possible relationship between mental deficiency and diabetes. Diabetes is recognized as having hereditary characteristics, both active and as carriers, to have distinct biochemical dysfunction, and to be associated on occasion with congenital anomalies, and retarded sexual and somatic development.

The institution in the future must be able to use effectively a better form of nomenclature than we have available today, must be able to diagnose more closely and accurately than we do today, not only the gross variations but also more detailed biochemical variations, and must be able to establish all this data in a more comprehensively usable form of records.

I believe somewhere in the past we in the field of institutional mental deficiency had fostered on us a sense of omnipotence we must very quickly shed. We have permitted the parents and the public to convince us we should give a cradle-to-the-grave type of care to the mental defective. We have in accepting this huge responsibility achieved rather low professional status and have permitted both the parent and the public to escape from responsibility rightly theirs. We have attempted to give total care permanently when in reality we had few specific and valuable techniques to offer. If by the chance growth and development the patient improved, we could modestly accept the praise given us. If the patient died we could piously hope for a better day in which we would have the skills and tools to do better. If the patient just remained the same we could explain that his conditon did not permit him to achieve to a higher degree of conforming to expected behavior. Yet in most instances, no matter just what happened we had few fundmentals by which to evaluate the end result. If you doubt this statement, sit down and try to outline, in a convincing manner, to yourself a satisfactory technique for toilet training. I believe we have none. In a similar manner, much of what we accept as training of the patient may really be training of the rest of us to accept the conditions the patient presents.

How else can we rationalize our acceptance of groups of forty, sixty or eighty enuretic and incontinent mental defectives in these institutions as under training. By assuming responsibility for long-range, long-time care we have taken advantage of the factors of time and chance and have thereby hidden our actual ignorance even to ourselves.

It is my conviction that the institution for the future to fulfill its purpose must be able to admit its patients rapidly, without long periods of time on waiting lists, to bring the patient into a controlled really therapeutic environment without mass grouping of persons, and to approach these patients medically, nutritionally, psychologically, and educationally in a manner generally unknown to us today. It would seem that the length of institutional stay should be shortened extremely and the patients returned to their homes and community for continuing care long before the patient has been completely emotionally expelled from membership in the family group, and before the patient and his family becomes dependent upon the institution. This would undoubtedly mean additonal responsibility upon the family and upon the community and would no doubt mean closer collaberation between the institution and community facilities, and reorienting and encouraging the family in continuing treatment. This would undoubtedly also mean frequent readmission of these patients to the institution for additional therapy. To advocate such a radical program of treatment I am certain would produce severe resistance on the part of many families and most community agencies. Such an institution would also require a more efficient team of individuals using better techniques, studying their patients more completely, less empirical treatment and using treatment modalities at present unknown.

If I could tell you how to do these things I would not be projecting into the future, but would be probing the present. For many years and until Joshia Slocum did it, people believed it impossible for a man to sail alone a small boat around the world. The belief existed, contrary to fact, only because no one had ever done it. I would not fear that our current lack of effective treatment would continue long, for we must remember approximately half of the effective medications used today in medicine were unknown much beyond the last decade.

I believe we are not wrong in believing that some day many of these conditions classified as mental deficiency will be amendable to sound treatment and care. We are seeing the beginning today. How fast we advance will to a degree be dependent on ourselves and our institutional practices. Folling described the phenylketonuric individual in 1934. We can decry that about a quarter century later there is still not effective treatment available. It took us at Polk State School until 1946 or twelve years to determine how many we had. I assume not every institution of our type in the country knows its inventory of phenylketonurics yet. How fast Mark and the Gerber investigators and others go forward depends in part on the pressure demand for a treatment.

We are seeing today splitting off of small segments of this composite group of mental defectives that are approachable, and understandable on a biochemical basis. We are beginning to see surgery playing an increasing role interrrupting those conditions which if left untouched would result in a degree of permanent incapacitation of the individual as a mental defective.. It is far more challenging

to hear a man like Eugene Spitz, M. D., of Philadelphia, speak emphatically that a subdural hematoma must be drained before nine months than to listen to a physician tell a parent to wait a while longer as the child will probably outgrow the condition. It is startling to find in one's own institution at least fifteen patients who undoubtedly are institutionalized mental defectives today because someone failed to recognize a subdural hematoma which existed and which probably could have been removed with negligible risk to the patient if the treatment had been known and instituted at the time they received the injury.

We are involved today in semantic consideration as to whether these institutions for the mental defectives are schools, homes, or hospitals. What they are called is less important than what type of service they render. Most of these institutions do not approach the patient with as nearly a present day application of knowledge and practice as is encountered in other types of organizations treating general medical or surgical conditions, or those places treating rehabilitative conditions in the paralytic person.

These institutions will not reach true hospital status thru merely adding to the staff individuals to give service in ever increasing areas of the patient's life. The institutions can reach true hospital status when they can and do provide a setting for detailed study of the individual patient, developing not only a symptomatic portrayal of his condition, but more importantly seeking to relate symptoms to more basic causative factors, genetics, psychological, physical, and biological. Then treatment should and must follow rapidly, completely, and involving all those areas indicated.

It seems unrealistic to hope we will ever build enough bed space to house all the mental defectives who may need institutional care. It is unrealistic to hope we will soon have enough bed space to eliminate the present waiting lists. It would appear realistic for some few good institutions properly situated with regard to medical school and research facilities, to admit only selected fresh applicants on a pilot basis. This might, because of costs and personnel requirements, require heavy prolonged National Institute of Mental Health expenditures and Council of State Governments support. Most of the service type institutions giving care to the mental defective patient can probably not be looked upon as being really potential for this type of usage.

There will undoubtedly evolve institutions in the future that will be hospitals in the true sense, and which will be active communities for aggressive treatment. Each of these, no matter where they be, will awaken the interest, thought and cooperation of those in allied sciences and disciplines to help create new understandings and new techniques. I can envision them as laboratories in which new thought and new regines are attempted in new patients who have not been conditioned by half a lifetime of living with their defects.

There will undoubtedly also remain many institutions for the mental defective that will continue to follow the pattern of the past. To these must fall the lot of giving custodial care for years to those least responsive to treatment. To these less fortunate institutions the picture is clear. As we have today insufficient staffing, insufficient facilities, a little professional regard - so will these conditions become increasingly severe and more ciritical in the future. They will become mere boarding houses for idiots, and the staff only the keepers of these boarding houses.

I am not certain whether our society and we as professional workers in the field will have the courage and the conviction to turn our back upon a great deal of the tradition these institutions have developed in the past and to work towards making the institutions into newer form for the future. We will undoubtedly meet opposition and disappointments. We will make mistakes. I believe the role I have attempted to outline can be achieved within our professional lifetime. The stakes are high for the professional worker. It is either hospital or zoo!

Thus it appears there will be two types of institutions for the mental defectives in the future. One shall be an instrument of humanity, the other must be a direct linial descendent of bedlam. I see only two paths open to us. I cannot forsee which path we will follow. The situation facing us seems well summed up by an old Biblical Statement, "The race is not to the swift, nor the battle to the strong, neither yet bread to the wise, nor yet riches to man of understanding, nor yet favour to man of skill; but time and chance happeneth to them all." (Ecclesiastes IX II.)

State and Local Governments under Pressure

(1) Business Review December 1957

WHO NEEDS AN INSTITUTION?*

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In the past, the intended functions of residential institutions for the mentally retarded have been two: (a) training of the more intelligent patients for living in the community and (b) custodial care of the less intelligent patients for the remainder of their lives. The general trend in institutional populations has been an increase in the proportion of custodial patients. More and more, the institutions for the mentally retarded are becoming custodial centers.

Concommitant with the increased custodial function of the institution has been a constant pressure to admit even more custodial patients. As facilities for the severely mentally retarded become available, they are rapidly filled and other facilities are requested. We are faced with the problem of having a large eligible population which is unable to take advantage of the institution. Inasmuch as not everyone who desires institutional placement can be accomodated, we must decide who really needs an institution. At the same time, we must revaluate the intended functions of the institution.

Traditionally, the place of children, regardless of their physical or mental health, has been at home. It is considered a tragedy for children to live away from their parents regardless of the adverse effects upon the parents or the children themselves.

It has become customary among all segments of our population to accept institutionalization when the parents are unable financially or physically to care for the child, that is, when the parents are unable to carry out their traditional functions in child raising.

Despite the traditional emphasis on parental financial and physical health obligations, one of the most profound cultural drifts in contemporary society is the growing stress upon social and emotional relationships. This general movement is perhaps best represented by current interest in mental health, provisions for mental illness, and effective group relations.

In view of the problems relating to mental illness, mental health and effective group relations, a second criterion arises as to the advisability of placing the retarded child in an institution. We can ask three questions: (a) Under which conditions does the presence of a severely mentally retarded child affect other family members adversely? (b) Is institutionalization effective in counteracting the effects of a severely retarded child on his family? (c) What other steps besides institutionalization must a family take to counteract adverse influences of the mentally retarded child?

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*This paper is based on a study, "Effects of a Severely Mentally Retarded Child on Family Integration." This investigation was supported by a grant from the Mental Health Fund of the Illinois Department of Public Welfare.

Study of Family Integration

A study was undertaken of families with severely mentally retarded children in the Chicago area by the Institute for Research on Exceptional Children in cooperation with the Illinois Mental Health Service. The sample studied was restricted to families with the following characteristics:

A. Both parents Caucasian.

B. One child in the family regarded as severely mentally deficient by one or both parents. With minor exceptions, the mentally retarded child was one with an I.Q. of 50 or under.

C. The mentally deficient child was aged 16 or under.

D. The parents were married and living together at the time of the study.

E. The mentally deficient child was born in the present marriage.

F. At one time or another, the parents had been in contact with a parent's association for promoting the welfare of the mentally retarded.

In general, the parents who participated in the research had been married about fifteen years, were in their first marriage, were about forty years of age, had a median income of nearly $6,000 per year, had at least a high school education, were in white collar occupations, were native born, and had about three children. In one-third of the families, however, there was only one normal child in addition to the retarded child. The religious preference of almost half of the parents was Protestant; approximately one-third were Roman Catholic; about a sixth were Jewish; and the remainder reported either none or did not respond to the question on religion.

In the collection of data, two interviewers visited each family in their home at an appointed time. While one interviewer talked with the husband, the other interviewed the wife. The interview, which lasted about two and one-half hours, consisted of two parts.

The first section was a face to face interview in which the respondent was asked to elaborate on various matters pertaining to the family and the child's handicap. Interviewers recorded the responses verbatim.

The second section of the interview consisted of a questionnaire in which the responses required were multiple choice, check mark, or a number. The second part of the interview included an index of marital integration, a sibling role-tension index, a modification of a Vineland Social Maturity Scale, a social mobility scale, and a neighborliness scale in addition to questions on basic social data.

Results of the Study: I. Attributes of the Child

There were two stages in the analysis of the data

The first stage of the analysis was concerned primarily with the questions of conditions under which the presence of severely mentally retarded children affected family integration adversely and general effects on the family resulting from placing the child in an institution.

Other studies have shown that in families with normal children, marital integration tends to be fairly constant from early to middle years of marriage regardless of the number or sex of children. On the basis of questions pertaining to the pre-marital situation and early marriage, we made an estimate of the probable marital integration of the parents had no retarded child been

born. We were thus able to account for influences on marital integration other than the presence of the retarded child himself.

Some of the results obtained in the study are reported below:[1]

1. Parents with a retarded boy were more often adversely affected in their marital integration than parents with a retarded girl. This result was interpreted as stemming from a difference in parental aspirations for normal boys and girls. The normal girl is expected to marry and have a family whereas the normal boy should eventually achieve a status in the community held equal to or exceeding the status of his father. With the girl's career defined generally in terms of home and family, an evaluation of the girl is based on her ability to help with housework and on her personal appearance. The boy, however, is generally evaluated on the basis of his extra-family relationships. His progress in school or prowess in athletics form a basis for evaluating his development. The severely retarded girl hence is able to conform more to her parents' expectations than can a retarded boy.

2. Parents of retarded girls generally had a higher degree of marital integration than parents of retarded boys, regardless of social status in the community. However, the difference between the marital integration of parents of retarded girls as compared with the integration of parents of retarded boys was greater in low social status groups than in higher social status groups. This finding is consistent with results of other studies, which indicate that greater emphasis is placed on differences in the roles of boys and girls in lower social class families than in middle-class families.

3. In the comparison of the marital integration of parents with a child in an institution with that of parents with a retarded child at home, the findings were:

a. There was little difference in the degree of marital integration between parents of a retarded girl at home and those with a retarded girl in an institution. This finding is consistent with the interpretation that the retarded girls do not impose a severe strain on their parents' marriage. The case material in the investigation suggests that frequently parents of retarded girls suffered intense feelings of guilt over placing their daughter in an institution.

b. The marital integration of parents with a retarded boy in an institution was generally higher than the marital integration of parents with a retarded boy at home. Relative to the results pertaining to parents of retarded girls, the findings indicate that on the average the presence of a retarded boy has a severe effect on his parents' marriage.

c. There was little difference in the degree of marital integration between parents of a retarded boy in an institution and parents with a retarded girl in an institution. Placing the child in an institution, leaves the family in a situation much like that of families with normal children only. Hence, with the retarded child removed form the home, the number and sex of the normal siblings have little effect on the marital integration of the parents and the

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[1] The results of the first phase of analysis were included in Bernard Farber, "Effects of s Severely Retarded Child on Family Integration," Monographs of the Society for Research in Child Development. (In press.)

family is similar to those with normal children only.

The comparisons relating to the marital integration of parents with a retarded child at home and parents with a retarded child in an institution support the contention that having a retarded boy has a more severe effect on the parents' marital integration than does having a retarded girl. The adverse effect of the retarded boy on the family is reflected in statistics relating to admission to institutions. In 1955, the median age for trainable boys admitted to Lincoln and Dixon State Schools was 6.6 as compared with 10.2 for trainable girls.[1] The data on admissions, taken in conjunction with the results of the family study, provide additional evidence of relatively greater impact of the presence of a retarded boy than of a retarded girl on family relations.

4. With regard to the problem of whether to place the retarded child in an institution while he is young, it was found that:

a. When the retarded boy was young, there was little difference in marital integration between parents whose retarded son was at home and parents whose retarded son was in an institution.

b. However, among families with older retarded boys, parents whose retarded son was at home tended to have a lower marital integration than parents whose retarded son was in an institution. For this analysis, a young boy was defined as being nine years of age and less and an older boy was between the ages of 10 and 16. This comparison of families with a retarded boy at home and families with a boy in an institution seemed to indicate that as the retarded boy grows older, he tends to exert an increasingly disruptive influence on the relationship between his parents. According to the conceptual framework which was used as a basis for the study, the retarded child's slow or decelerating development increasingly removes the parents from participation in many of the normal activities of community life. The parents tend to become alienated from the community and often do not find emotional support for the validity of their decisions in family life. Hence, it is reasonable that older boys would have a more disruptive effect on their parents' marriage than younger boys.

5. In the analysis of data on normal siblings, the findings were:

a. Normal sisters of a retarded child at home showed more characteristics of maladjustment than normal sisters of a retarded child in an institution.

b. However, in contrast, normal brothers of a retarded child living at home displayed fewer characteristics of maladjustment than normal brothers of a retarded child in an institution.

The interpretation placed on the findings that normal brothers and sisters have different responsibilities toward the retarded child at home. Taking the retarded child out of the home would then have a different effect on their adjustment to his institutionalization. With the retarded child in the home, normal sisters would be expected to help care for him. Normal brothers, however, would be encouraged to develop and maintain contacts out of the home which would give their mother as little trouble as possible.

[1] Illinois Department of Public Welfare, Statistical Research Section, Director's Edition - Statistics, Dixon and Lincoln State Schools for the Mentally Deficient, July 1, 1953 - June 30, 1955, Springfield, Ill, Dept. of Public Welfare, p. 15.

With the retarded child in an institution, however, a normal sister would be relieved of her surrogate responsibilities while the parents increased their expectations of conforming conduct and responsibility on the part of the brother. Whereas, before the brother went unnoticed, now his misbehaviors would be closely watched. It is significant that several brothers, but no sisters, expressed the fear they might be sent to an institution with their retarded sibling if they failed to behave properly.

If the family's obligation in the child's socialization is defined primarily in terms of physical care and financial support, the institution can take over this function without involving the whole family. If children are accepted by the institution in order to maintain the mental health and integrity of the family, however, it is possible that the service of the institution should be extended to maximize the mental health of the family.. The question was asked: Which steps besides placing the child in an institution are needed to counteract adverse influences of the retarded child on other family members?

An answer to this question is suggested by the results of the second stage of the analysis of our data, dealing with family organization.

The social organization of the family can be described in terms of orientations of its members toward family and community. When we compared families with a retarded child at home and a retarded child in an institution regardless of the sex of the child, there was no difference in the degree of marital integration of the parents. The results were striking, however, when we viewed the families as characterized by their value orientations.

The problem arises: What are the family orientations found in families with retarded children where a high level of marital integration has been maintained?

On the basis of a conceptual model, families were classified as falling into one of four categories: (a) child-oriented, (b) home-oriented, (c) parent-oriented or (d) a residual classification for all families not having the characteristics required for one of the first three categories. The families in the first three categories seemed to have a focus around which to organize the lives of the individual family members. This focus or orientation seemed to provide a basis for the consistent attainment of gratification by the parents. The orientation, hence, was regarded as conducive to high marital integration.

For classification in the first three categories regarded as favorable to marital integration, a family had to have the following characteristics:

A. The integrative child-oriented family was one in which both husband and wife were favorably inclined toward high social mobility; the husband emphasized traditional rather than companionate values in family life; the wife identified highly with at least one of her normal children; under certain conditions, interaction between normal and retarded siblings was limited; and emotional support was provided by the wife's mother or the community.

B. The integrative home-oriented family was one in which either the husband or wife cared little about social mobility; the husband stressed companionate values in family life; under certain conditions, interaction between normal and retarded siblings was limited; and either the parents were highly integrated in the neighborhood or the husband identified highly with his wife.

C. The integrative parent-oriented family was one in which the parents were favorably inclined toward a high degree of social-mobility, the husband stressed companionate rather than traditional values in family life, and the husband identified highly with his wife.

All families which lacked any of the characteristics required for classification in one of the above three categories were placed in a fourth category. In the first three categories, the families were regarded as having a focus around which to organize the lives of the family members so that they could achieve mutual gratification of their goals. The families in the fourth or residual category, however, were regarded as either (a) lacking in focus or common orientation or (b) being organized in its system of roles in such a way as to impede gratification pertaining to common orientation. Hence, the residual category was considered as the grouping of kinds of family organization not conducive to high marital integration of the parents.

On the basis of an analysis of cases, indices were derived for classifying all families in the study as (a) parent-oriented, (b) child-oriented, (c) home-oriented or (d) residual family organization. The results are summarized briefly below:[1]

1. Whether the child was at home or in an institution, parents in the child-oriented, home-oriented, or parent-oriented category tended to have a higher marital integration than those parents in the residual or fourth category.

2. Restricting the analysis to those families who were in the child-oriented, home-oriented, or parent-oriented category, we found that for families in these three categories, those parents who had placed their retarded child in an institution tended to have a somewhat higher marital integration than those parents who kept their retarded child at home.

3. However, among families who were in the fourth or residual category, there was little difference in the degree of marital integration between parents whose retarded child was in an institution and those parents with a retarded child at home.

We infer from the results that:

A. If the family is consistently child-oriented, home-oriented, or parent-oriented (as defined by our criteria above), parents may often be able to keep the child at home--regardless of whether the retarded child is a boy or girl--without seriously endangering the integrity of the relationship between the parents.

B. The best single solution for parents is (a) to place the retarded child in an institution and (b) to develop or maintain a consistent child-oriented, home-oriented, or parent-oriented family organization.

C. If the family is not consistently child-oriented, home-oriented, or parent-oriented but instead falls into the residual category, either of two steps could be taken eventually:

A. The child may be placed in an institution while the parents are given counseling to enable them to develop a consistently child-oriented,

[1] Details and qualifications concerning these results will be incorporated in a monograph now being prepared.

home-oriented, or parent-oriented family organization (depending upon the parents' value system). After the completion of the counseling, the decision can be made as to whether or not the retarded child is to return home either permanently or on a trial basis.

b. The retarded child may be kept at home while the parents are given counseling to enable them to develop a consistently child-oriented, home-oriented, or parent-oriented family organization.

Needed Research on the Family with a Severely Retarded Child

The results of our research, of course, pertained primarily to the child who is placed in an institution because of adverse effects on the family. It was not concerned with the child who is placed mainly because of problems of physical care or financial or legal dependency. Nor did our investigation touch upon the mental health of the retarded child himself.

The results of the study introduce many additional problems for research. Relative to the number of families with severely retarded children, the research thus far has utilized only a small, highly-urbanized sample of essentially middle-class families. This bias in sampling may have influenced the findings. Perhaps, even more important is the lack of reliable knowledge concerning the nature and development of the integrative family orientations. For example, we do not know what happens to the normal siblings in these family orientation types. We do not know the process by which families develop these orientations. Nor do we know whether orientations were introduced prior to or after the birth of the retarded child. We do not know the ethnic, regional, religious, economic, or educational backgrounds which facilitate developing certain family orientations. Instituting post-placement parental counseling would itself generate research on therapeutic techniques and effectiveness of counseling. Finally, continued investigation of the process of discovering that one has a retarded child, the process of institutionalizing a retarded child, and on communication in families with retarded children, may eventually provide a reliable basis for deciding who needs an institution.

Summary

The problem of effects of a severely mentally retarded child on family integration was studied for a middle-class segment of an urban population. The age and sex of the retarded child, the social class of the parents, and the religion of the parents generally affected the degree of marital integration of the parents of a severely retarded child. It was also found that sending the retarded child to an institution seemed to help the family relations of the normal sisters but seemed disruptive of the family relations of the normal brother.

In addition, the results indicated that families with certain parent-oriented, child-oriented, or home-oriented activities and values were characterized by higher marital integration of the parents than other families. For the sample studied, among families who utilized the integrative orientations, those parents who placed their retarded child in an institution tended to have a somewhat higher marital integration than those who kept their retarded child at home. Among families who did not utilize integrative orientations, there

was little difference in marital integration between parents whose child was in an institution and those whose child was at home.

The results suggest that, depending upon the specific circumstances present in a family:

A. Retarded boys be given priority in institutional placement.

B. A post-institutional parental counseling program may eventually permit the release of patients who can be cared for at home.

C. The optimal solution for parents is to place the retarded child in an institution and utilize certain forms of family organization.

The suggestions cited above require much qualification because of the complexity of specific research findings in the study briefly summarized in this paper. In spite of the suggestiveness of the results, however, the limitations of sampling and conceptualization of the research demand that further research be done on the problem of who needs an institution.

PREADMISSIONS, RELEASE, AND AFTERCARE SERVICE

By

Mrs. Sadie E. Smith
Executive Secretary
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In trying to decide how I should approach this subject, I found my thoughts repeatedly reaching out for anchorage into the broad field of total community resources for the mentally retarded, including within that totality the institutional program. Certainly neither the act of getting into an institution nor that of getting out can be dealt with appropriately, apart from some consideration of the larger community environment with its social processes, attitudes and resources.

To go a step further, these two "ends" of institutionalization, that is, preadmissions on the one end, and release and aftercare on the other, depend equally in their effectiveness upon the kinds of services that are available in the community and those that are available in the institution.

PREADMISSIONS

Several social workers have written quite effectively on the subject of preadmissions in the last few years, and I think the purposes of preadmissions work are now fairly well known and accepted by institutional personnel. Thus I will not attempt to discuss them in detail but will merely recall some of the more important ones for you, so that we will be better able to think together about some of their implications. They are as follows:

1. To help acquaint the parents with institution program and procedure so they can decide more intelligently whether the institution offers what they want for their child.
2. To offer casework help to the family with difficult problems that may arise while the person is awaiting admission, or assisting them in a better understanding of the retarded individual.
3. To study and evaluate the family situation and the patient's place in it; obtaining their cooperation and participation in planning for him.
4. To help the child or adult in the transition experience from home and community to the institution.
5. To eliminate the admission of persons for whom the institution has little or nothing to offer, and for whom as good or better plans could be made in the community. This might include referral of the family to other community resources or helping them to work out an alternate plan.
6. To determine which cases are most urgent (where there is a waiting list) and should receive priority consideration for admission.

It is easy to see that there can be many gains for the patient, the family, the institution, and the community in this kind of a program; and it is good to know that an increasing number of institutions are incorporating these services into their total programs. At the Columbus State School, one of the major purposes in setting up Regional Offices in Cleveland and Cincinnati was to be able to make available these preadmissions services to many more families in the state, so important were they regarded. However, they might be carried out also, through

such methods as traveling professional teams when a large geographical area must be covered, or simply out of the institution itself, with services provided by the Social Service staff.

If we were to try to chrystallize the purposes of a preadmissions service into a single objective, we would probably say that what we are after is selective admissions; selective in the sense that any admission is based on the needs of the patient and his family, and what the institution can offer to meet these specific needs.

We remember well that there was a time, not too long ago, when retarded persons were sent to institutions because there was nothing in the community for them. Now, all of that is changing, and Parent Groups all over the country have played a large part in this. In many localities there are special classes for trainable children besides the slow learning classes in the public school system for the educable group. Although fewer in number, there is a growing list of Day Nurseries and Day Care Centers, Sheltered Workshops or Occupational Centers and special recreational programs. I have been tremendously impressed with this in my work in Florida through the reports I get on activities of this type, from nearly all parts of the country.

The obvious corollary to this is that the role of the institution is changing, or more accurately, is beginning to change. It is becoming one part of the total community resources for the mentally retarded, rather than the only service or available plan of care. Therefore, it would appear that it will be possible to use the institution more constructively and selectively in the future, in proportion to the establishment of additional community resources. What we have said, in other words, is that meeting the needs of the retarded person as effectively as possible is dependent upon total community resources, including the institution.

This brings up another significant factor in preadmissions work, that is, the rights of the parents in planning for their child, freedom to make choices, to utilize or reject suggested ideas or plans. Too often in the past, and even now, these rights were taken over by court officials, physicians, social workers or psychologists. Our institutions have many persons within them whose families have remained bitterly unhappy for years on end because the decision to institutionalize was not theirs and their rights as parents and persons were ignored. (Granted that there always will be a few who have lost their rights through deprivation or neglect of their children.)

It would be a serious error ever to lose sight of the important place the parents occupy in the lives of their children, even though the latter may be far away from them in a state institution for a period of years. Surely we are all in agreement that there is nothing in the life of anyone that can compare with the dynamic implications of belonging, of being loved and wanted by one's own family.

When we have recognized the parents and helped them to retain their rightful place in their children's lives, in early preadmissions contacts, we have, at the same time, set the stage for the most productive kind of institutional experience for the children. In many cases, we have contributed, also, to the mental health of the parents, bolstering their feelings of worth and importance which have often received quite a blow in their previous experiences with their retarded children.

It seems essential, too, that we face up to the fact that in this field, as in no other, perhaps, the education and training of the parents should go along with

that of the child, starting in the preadmissions services. I have seen family situations which in some ways appeared to be very neurotic ones, but on further study the major problem seemed to be no more than normal frustration at not being able to understand or cope with their child's abnormal behavior and development, or deal with his unique training needs. The state of New Jersey has for many years had a training program for parents which has had a marked degree of success. As I recall it, this program is especially designed to aid the parents in the care of the child during the preadmissions period.

In recent years the institutional team has rightfully been an expanding one. Even more in the future, I believe it should be enlarged to include not only the parents but also the community, in order to carry out the kind of program that will best meet the needs of the greatest number of persons.

RELEASE AND AFTERCARE

From preadmissions we take a long jump to release and aftercare. Of course, it is assumed that not only have our patients and their families gotten off to a good start in a preadmissions program, but effective training and treatment plans have now been realized with release from the institution being the next important milestone in the life of the patient.

Several months ago I read an article in the Columbus Dispatch in which an Ohio State University professor, whose name I cannot remember, quoted a definition of education which I jotted down. In the quote, education was described as "the cultivation of a valued human being". (Perhaps some of you educators may know the source - I do not). Nevertheless, it seemed to come as close as anything I've ever heard to describing what we ought to be doing in the training-treatment process that is institutionalization. This is a concept that can and should apply to every human being who comes within our walls.

Let us think about it for a moment. "Cultivation" -- developing, training, causing to grow, paying close attention to -- these are some of the appropriate meanings for us. "Valued" human being -- the child who is "no less precious", who is entitled to all the benefits and services that exist for children everywhere or anywhere -- this is education and training in its highest form. It strikes at all that is basic in preparing persons in the institution for a satisfying, productive life in the outside world.

Teaching our people how to live within their disability, giving them a way of life, helping them to be at peace with themselves and others -- this is the essence of what they need most of all. Such an approach might also be described as personality development and enrichment. From my own experience and that of others in similar positions, I know that most of our young people who do not work out successfully on jobs in the community, fail to measure up, not because they are unable to master the technical skills involved, but because of personality problems that get in their way, preventing them from utilizing their abilities to the fullest extent, or in an acceptable way.

Having spanned the interval from preadmissions to release and aftercare, we find it impossible to talk about the latter without bringing the community back into the discussion.

It is obvious that if the institution is used selectively and purposefully, a

great many patients will be enabled to return to the community. It is just as obvious that if many are returned to the community, they will need to be transferred to and absorbed by the health and welfare services in the community that exist for all the people. Institution personnel, which would be the social service staff in this case, could not be built up fast enough, even with very large budgets, to supervise indefinitely the ever increasing number going out from the institution. It seems to me that the institution has served its purpose well and discharged its responsibility when it has trained these retarded people to the point where they can again take their place in society, and in varying measures according to their respective abilities and limitations, become good citizens and useful members of their communities.

To be more specific, let us see what some of the conditions of release are, or what qualifications are important for community placement. The following have seemed to be useful in my experience, as related to work placement and family care. Only the first six, however, would be especially pertinent for those going out on Family Care.

1. Patients should be able to accept and use authority.
2. They should be able to follow directions and instructions.
3. They should have respect for the rights and feelings and possessions of others and be reasonably able to get along with others.
4. They should have practical working knowledge of self-care, good grooming and personal hygiene.
5. They should have demonstrated some ability to conduct themselves with relative ease in simple social situations, and understand what is expected of them.
6. They should be in reasonably good health, depending upon the type of plan for them in the community.
7. They should have had an introduction to what it means to live in the community, know how to get around and use the bus, and be able to locate facilities such as the post office, stores, etc.
8. They should have had whatever training they could utilize to advantage, academic, pre-vocational, vocational, that would help to prepare them for a successful job experience.

In other words, it is simply that they should have the kind of training, capacities and personality that will make for ordinary, everyday, good citizenship, granted that the requirements of the individual would be much less or different in some situations than in others.

While it is true that many will need a continuing, supportive type of service, some will require some form of financial assistance for the remainder of their life time and others will need occasional help in crisis periods, this is nothing new to the community. These people are not unlike thousands of others in this characteristic of needing help, nor in the kinds of help they require, nor in the use they will make of the help they get. Furthermore, there are existing, public and private health and welfare agencies through which this help can be given.

There is a big job of community education to be done but even as life in the institution merges more and more with that of the community, as I believe it should, this job of public understanding and acceptance of responsibility will take care of itself in increasing measure.

Besides, there is no better public education device than those programs carried on by the institutions in the community, such as Family Care and Work Placement. Through their work, and their community life and activities, the patients themselves indirectly tell the story, which is the most effective of all methods I know. Add to this, innumerable, continuous contacts of institutional social workers with employers, agency workers, schools, boarding home parents and prospective ones, families and relatives, and this makes up a sizable public education program even if nothing of a more formal, structured nature, is done.

Now, I have not attempted to define work placement, or family care, nor deal with the common components of either program, because I know all of the states represented here have strong on-going programs in both areas. Instead, I will try to examine some aspects which have been dealt with less frequently, perhaps.

In fact, I have already touched upon one problem when I indicated the number of those persons released from institutions would eventually become so great that they could not be carried by the Social Service Staffs. Another valid way of looking at this is that these people are the legitimate responsibility of the community at the point of their release.

Many institutional staffs feel that they are in a position to give better services than other public and private agencies to their people who are in the community, and therefore they are obligated to do so. While there is much to be said in favor of this kind of reasoning, it is possible for us to become too possessive and too protective, often at the expense of the patients themselves as many programs and services for which they might be eligible and could benefit, are simply not available to them. I refer to family and child welfare agencies, both public and private, public assistance agencies and group work and recreational centers. In Ohio, the number of agencies that became interested in working cooperatively with the institutional staff, was a constantly growing one. Some were doing home studies and evaluating potentials of the home for the patient's return, some were accepting referrals of preadmissions cases for services of various kinds, others were supervising patients in the home on trial visit, others were supervising patients in the home on trial visit, others were doing diagnostic evaluations prior to commitment. ADC increased grants to enable children to be at home during vacations and extended periods of time. Others, such as Aid to the Aged and Aid for the Disabled, accepted responsibility for cases that could meet their eligibility requirements, in still another way. They took over financial responsibility and in a period of a year or so, according to plans worked out between the two agencies, the patient could be discharged from state rolls, and the other agency would take over complete responsibility for the case.

All of these services are invaluable from two additional standpoints: (1) they extend greatly the services of the institutional Social Service Staff which is none too large at best, in most institutions; and (2) they represent another effective channel of public education. We have said that mental retardation is the business of the entire community. Let's make sure that we are doing all we can to encourage such an attitude.

It is true, however, that it may be necessary for the institution staff, in some instances, to actually demonstrate over a period of time, the validity of certain services for the retarded, which, hopefully, might later be taken over by a community agency. This may well be the case with newer phases of program development. Sometimes this may be necessary; also for the purposes of study and our own learning.

Aftercare services can take many forms but as in all work with the mentally retarded, few blue prints are available. Creativity, ingenuity, and sensitivity to the meaning of what our patients are saying and doing as we work closely with them, will go far in helping us to chart a course that will produce results. No one has very many answers yet, and there is unlimited room for new ideas. Let's not be afraid to try out some of them.

Along this line, I was very much interested in some of the experimentation as described in the final chapter of "New Directions for Mentally Retarded Children", a report on a conference requested by the Interdepartmental Committee of Children and Youth, held at Princeton, N. J. In February 1956. Isabel M. Laird, now connected with Canada's mental retardation program, but with much experience in her own country, Scotland, and in England, told of over 150 Occupational Centers in Great Britain where trainable mentally retarded youth and adults, many of them mongoloids, who are considered unemployable by industry, are doing many types of work and having experiences often thought of as impossible, and certainly unusual for this group. They are making an excellent contribution to their own welfare and to that of the community as well.

Miss Laird believes that these centers can be started without elaborate equipment or huge expenditures. Many were started during the war in England when there was no money for materials. For example, in one occupational center, they made fireside brushes of odd pieces of rope and door mats from old tires. However, Miss Laird did point out that one has to use some ingenuity in making good use of these discarded or inexpensive materials.

In Leeds, she described a municipal laundry now in operation for more than 10 years where there are only 3 regular employees, and the rest of the help consists of these so-called unemployable retarded women. For the boys there is a tailoring, boot-making and repairing establishment where they make the clothing for those in institutions for the mentally retarded. It is my understanding that many of these people go out from the institutions to work in the Occupational Centers on a day basis.

In the town of Wakefield, where there is an institution for adolescent girls, their first rehabilitation work is in a biscuit factory, where there are only three regular paid employees, with as many as 30 girls from the institution working there. They produce a high type produce, among the best on the market.

A final example of what they are doing, and something quite different, but possible almost anywhere, is a garden project. The town of Sunderland has given over some acerage where boys over 16, under supervision, grow all the vegetables for their own families, for the use of the Occupational Center out of which they work, and for private sale. This is their outdoor work. On rainy days, they work indoors, repairing furniture belonging to the municipality.

These are only a few of the examples given but it was a joy to read about them because it shows what can be done with a goodly mixture of hard work and ingenuity. They used what they had, and they have been free to experiment with what was available. This is a good combination and something was bound to come out of it.

While I am on the subject of work, and vocational training, let me suggest, too, that we get away from the habit of referring to all the retarded as "children", regardless of age or any other distinguishing factor. Granted, that many of the

adults possess childlike qualities, but just try to sell an employer in the community on the idea of hiring one of these "children"! Frequently, employers, or prospective ones, have heard speeches by institution personnel, in which these people were not only referred to as children, but a point was more or less belabored that this is one of their major characteristics. Such generalities, although harmless in many ways, are sometimes difficult to cope with when staff workers attempt to persuade prospective employers, on the contrary, that the individuals they are trying to place are sufficiently mature to meet the demands of the employment situation.

To turn to another perplexing phase of aftercare, what about boy-girl relationships, dating, marriage? Probably no thinking person would encourage the marriage of mentally retarded persons, but it cannot be denied that all of this is in the picture for these young people are human beings. Because they are human beings, they behave like human beings. Children become adults, - physical and emotional maturation is a fact. This we have to live with and deal with to the best of our ability, with respect to retarded persons, the same as all others. It is far better that we face it as intelligently as possible than to ignore it or attempt to deny it. I think it is possible that there may always be a group of adolescents and young adults, primarily, in the community who will become involved in sexual delinquencies. It seems likely that much of this may be due to the lack of the usual normal outlets and means of expression of these normal feeling and urges. With limitations of judgement and reasoning ability, some will fall into socially unacceptable modes of expression. They will require institutionalization and removal from society for some period of stabilization and help. I want to stress the word "help" because we often fail to do much about this problem.

Moreover, we have all known of many cases of retarded persons whose romantic interests led to marriages which were poor ones from any standpoint. The persons concerned simply were unable to cope with the responsibilities of maintaining an adequate home, rearing children, occupying a place of respect in the neighborhood. These were people committed to the institution, sometimes including both parents and their children. They came for the training, the treatment, the help of all kinds that they needed but to which they had never been exposed.

A while ago we talked about the "cultivation of a valued human being as our goal. This makes the difference -- and we do have faith that this kind of a broad, training process will make a difference. Within it, boys and girls can grow up in as natural and homelike environment as can be created, with recognition and understanding of all their developmental needs. Ways will be found for them to live together, play together, and work together, providing as many constructive and satisfying outlets for their normal feelings and drives as possible. Varied activity and recreational programs, which will challenge these youth, drain off pent-up energies, and give them interesting things to do with their free time which they can make use of as they leave the institution and go out into the community, are very important. Individual counseling, or intensive casework services, will be needed in most instances, as they are confronted with problems of dating and marriage. These should all be available to help these young people in this greatest responsibility of all which some of them will undertake, whether we will it or not. At least the institutional staff will have discharged its responsibilities in giving the best preparation possible for those who do take this step.

I have talked about some aspects of Family Care and Work Placement, and now I return to the family with which subject I began this discussion. By whatever name the program for release to family is called, conditonal discharge, trial visit, or something else, its value can scarcely be overestimated, both for the patient and for the institution. It is a pretty well known fact that the welfare of any child, generally speaking, is best achieved in the nurturing, loving, protecting relationships of the home and family. The late Dorothy Hutchinson, well known professor in child welfare at the New York School of Social Work had this in mind when she once said in a speech I heard her make, that the best child welfare is a good home.

How strong and deep feelings about the family are, was often demonstrated in the years I worked in an institution. I could not count the times I have heard youngsters in the institution weave whole stories about their parents, brothers and sisters and the wonderful things they had done for them -- stories of parents and siblings who didn't exist except in the innermost yearnings of the heart of a lonely, scared child. Sometimes institution staff is inclined to be a bit reluctant to interrupt the training program of the child in response to requests of the family that he be permitted to go home. Of course there are circumstances which make it advisable for certain patients to remain in the institution irrespective of requests to remove them; but given a reasonably adequate family it is doubtful if there is any training the institution can give that can compare in significance with the unique contribution the family has to offer. It should be borne in mind that family circumstances and ability to keep the child or adult at home do change. Doubtless the best plan of all has been effected when we have enabled a patient to return to his own family.

There is another phase of this I want to mention: Sometimes institution personnel wait for the family to request the release of the patient before such a plan is ever considered, but this could and should work both ways. It is just as important that the institution staff see and use the home among the possible constructive resources for the training and rehabilitation of the patient. In such a case the family might be requested to try the patient at home for a given period, with a specific set of objectives in mind. Or, if the patient who is known to have a family and who could be cared for at home, has reached the point where he is doing little more than marking time, why not initiate a contact with them and investigate the possibilities of having them take him home? This might well be another positive method of getting people off the institutional rolls who do not need to be there.

SUMMARY

A brief summation of what I have said probably amounts to this: A good preadmission program and a strong release and aftercare program are essential in

1. eliminating the waiting list by keeping persons out of the institution who can be cared for as well or better elsewhere; and
2. getting people out of the institutions who no longer need to be there, or who have achieved maximum benefits and their welfare would be enhanced by moving them back to the community.

When one considers the possibilities in all of this, together with a growing community awareness and special classes and other services which are springing

up, a large question mark looms up as to the future that lies ahead. What will be the role of the institution? Will huge building programs be necessary?

In addition, it should be kept in mind that such programs can only be carried out with strong, well qualified, trained, professional staff, and in sufficient numbers to do the job well. Although social service workers will carry the major responsibility for these programs, the whole institution is involved in the task of admitting a patient, moving him on his way through the process of training and treatment to the ultimate goal of return to the community, that is, for as many as possible. Thus this is a part of a total program, all of which is moving in the same direction. If this is what we want we cannot skimp on staff. It will not be achieved that way.

In closing, I want to share with you a very precious little item that came to my desk this past week. It is written by the mother of a little boy who is in an institution in Michigan. She calls it "The Special One."

"He is five years old and small for his age. His name is Eddie, but he is called the Wee for one of those inexplicable and obscure reasons which become lost in the chronicles of a large family. He lives in an institution, and although his mother sees him only twice a month, he never leaves her heart. He is retarded, afflicted, exceptional and has been called each of these at one time or another.

But to his mother he is the special one. Special in ways known only to those who also know that the love of a mother for an afflicted child is a bittersweet thing. There is something special in the satisfactory way his hand seeks hers when they go for a walk. Although he cannot talk and they have never held a real conversation, there is a special tenderness in their limited and silent communication. His mother finds a very special pleasure in the astonishing music of his laughter when a sunbeam dances off a wall or a curl of smoke rides a stray breeze.

And it is during long walks, when the Wee and his mother stop occasionally to examine a small bright pebble or to see if snow tastes good, or on quiet drives with her cheek resting against his fair hair, that his mother will ask herself, 'Who am I?', and answer becomes quite clear. For she is one of those who know that they claim loving kinship with every mortal who has ever experienced the depths of sorrow and the reaches of hope, and she thinks, what a wonderful thing it is to know this.

Every mother who loves a handicapped child shares this knowledge. Her child may be called afflicted or exceptional but deep down in her heart this child will always be, to her... The Special One." (end of quote)

We share this mother's feelings, even though vicariously, for all the "special ones" as we move ahead trying to find some of the answers that still seem so obscure in this huge field of endeavor.

SOCIAL ROLE OF THE MENTALLY RETARDED

Mrs. Ruth Williams

Concepts about the role of the mentally retarded in our American culture are changing. Today the mentally retarded are not generally regarded as strange, weird beings possessed by the devil and thus to be shunned or isolated, but as individuals who have feelings and certain inalienable rights to happiness. Today we know all mentally retarded are not the same. They vary in abilities, talents and personality.

In view of the characteristic staggering overcrowded conditions in public and private institutions for the mentally retarded and long waiting lists, the nation and communities are examining their facilities and programs and finding the obvious--a paucity of resources. Society is deeply indebted to the parent groups for the current impetus toward examination of programs and development of services for the mentally retarded. Close behind come the increasingly concerned state departments of public welfare. Together, they are pressing professional workers--pediatricians, neurologists, psychologists, social workers, educators, sociologists, psychiatrists--to focus their knowledge and special skills on the health and welfare of this long neglected sector of our society. Questions are being raised as to whether there should be specialized agencies for the mentally retarded, or should established agencies serve them, or should not a community-wide plan include services from both types of agencies? One of the greatest problems that becomes apparent immediately upon the completion of any community study is the need for differentiation and individualization among the mentally retarded. The problem our society still imposes upon the retarded is the prevalent tendency and practice of summarily grouping all individuals below a certain intelligence quotient level as fit and proper subjects for institutional placement or custodial care, without regard for what is already known about the wide and meaningful range of strength and potentialities among these persons.

According to standard tests based on current scientific knowledge, approximately three percent of our population can be designated as mentally retarded. They are an integral part of our population and cannot be isolated. The care and treatment of this sizable population vitally concerns us, and we know they fall into three groups--the totally dependent, the trainable and the educable. By far, the largest percentage is in this last group. Experience proves they can be helped to be self-supporting with proper training and counseling. Many from stable families never come to the attention of the courts.

Professional workers concerned with the care and development of the mentally retarded are beginning to realize that no one approach is the answer for helping these people. Multiple approaches are required to deal with them most efficiently and constructively, and to achieve an understanding of them. In order for each mentally retarded child to develop to his fullest potential, an accurate diagnosis as to his potentialities and limitations should be made. Then treatment and training have to be planned to fit the individual needs of the child. A child with a speech defect might be helped with speech therapy, while attending trainable classes.

An aggressive, "acting out" child might be reached through play therapy before stabilizing sufficiently to attend more formal classes. A quiet, withdrawn adolescent might find self-expression and satisfaction through occupational therapy and thereby develop sufficient confidence to enter a vocational training program.

Historically, cultures have varied in their attitudes towards the mentally retarded. The Greeks wanted to destroy them; the Christians attempted to confort them. Traditionally Western European cultures have long made use of mentally retarded adults. Rural communities in England, for example, had their "dafties." These persons though usefully employed, were nevertheless placed in positions of ridicule, made the butt of hurting jokes. To the degree that today we note a sharp diminution of such anecdotes, present day cultures are defining in a more sensible manner the social role of their mentally retarded members--much in the same manner as for the physically handicapped. Everywhere, rural or folk cultures have been able to assimilate the retarded, including American sub-cultures from Folk backgrounds. Before the turn of the century, when our nation exhibited predominately a rural or folk culture, there were many chores that could be performed by the mentally retarded. They adapted easily to the more simple rural environment.

As the country has become more industrialized and our society urbanized, the mentally retarded have fitted into uncomplicated factory jobs. Some routine operations that would be monotonous to persons of higher intelligence have been satisfactorily performed by them. They also have found employment in service jobs, while more adequate persons have sought the less skilled jobs in industry and business organizations. In spite of, or perhaps because of, our technological and industrial advancement, gainful employment opportunities for the known retarded are harder to find and develop, generally speaking. Yet, on the other hand, as a result of our growing concern for the retarded and our scientific knowledge concerning their potentialities for certain types of industrial operations, nearly every sizable community has some small number of socially conscious employers who hire these people. Both these industrialists and their counter-parts prove conclusively that there are numerous, relatively simple industrial operations which the retarded can undertake, adjust to and succeed in performing, given management's will to use them. Again, as to management, the pattern is the same as in the employment of physically handicapped personnel.

The complex conditions of urban living, however, present the retarded with problems. Dr. Tredgold, who devoted ten years to a study of the mentally retarded in Great Britain, observed that they could be employed 'under favorable circumstances', but that they required supervised living. In line with this thinking, England, Scotland and the United States have to a degree developed colonies and halfway houses or transitional homes as a means of teaching mentally retarded adults how to lead useful, productive lives in a complex society. Tredgold's text book on Mental Deficiency in 1908 greatly contributed to the understanding of the mentally retarded. He considered mental deficiency as a psychological entity, but stated that the criteria for its determination are social. At that time he was concerned about what he believed to be the relationship between crime and mental deficiency--as are many people today, but numerous studies reveal that there is no larger a percentage of mental defectives involved in criminal offences than are found in the normal population. Furthermore, the kinds of offenses committed by the

retarded are less complex and not severe; also it should be remembered that by and large the less intelligent person is more easily apprehended.

In a civilization where there is emphasis upon intelligence, it is understandable that those who cannot achieve academically will have lesser status. This is a competitive social system in which value has been placed upon persons who excel in business and industry. Our current emphasis on the scientifically gifted might further detract from the status, the vocational training and the job opportunities of the mentally retarded because the tendency has always been to think in terms of contribution or value to society. But, unless automation becomes universal, manpower still will be needed for some of the simpler operations.

Certainly each child in the United States is entitled to a chance for his fullest development. If this commitment is to hold and be implemented for the mentally retarded child, then counseling with parents is mandatory. Undeniably, normality is valued in our mores. Counseling, therefore, with parents of the mentally retarded is of prime importance not only to the child's well being, but to the mental health of the parents as well. This means more than pronouncing a diagnosis. Effective counseling involves understanding of the family as a unit, the personality dynamics of the parents, starting with them where they are along with planning for the child's every-day management. Before a plan can be formulated, each child has to be studied as an individual.

With more classes for the trainable and educable available in communities, an increased number of retarded children of school age will be living at home. The inclusion of these children in educational and recreational programs will help change attitudes towards the retarded even more. There possibly can be no better public education to bring about respect and dignity for these children than for them to be cared for in the community, thus influencing people to learn to accept differences.

In families with high expectations for achievement, a child of more limited intelligence frequently is rejected, while this same child in a family with lower standards enjoys a feeling of belonging. These differences in family backgrounds have to be appraised in counseling parents. Sometimes when parents cannot cope with their retarded child, placement of the child in a residential setting is desirable, while the parents have a chance to work through their feelings and realign their defences. Karen is an example of a child whose parents benefited from counseling after they insisted upon her placement in a State school.

Karen was the youngest of three in a middle-class, suburban family. Her two older sisters were honor students in school. Shortly after birth, Karen experienced a prolonged infectious illness. On psychological tests she earned an Intelligence Quotient of 53. Her physical and mental development were slow. In addition, she was hyperactive and destructive. Both parents were concerned about having a "naughty, retarded child". According to the father, their physician urged them to abandon her. They decided upon placement at the State school when she was three years old. The father pressured for immediate admission, for he felt otherwise there would be imminent disaster to the family. After her admission, they maintained contact for two years, but discontinued their visiting when they felt their visits were confusing to Karen and frustrating to them.

When she was seven years old, Karen demonstrated special talent in art and showed interest to read and write, began to learn arithemetic at the State school.

By the time she was eight, her behavior had stabilized and she was more responsive. The social worker then had several interviews with the parents about their feelings toward Karen, and encouraged them to resume visiting her. They began to realize that while she might not learn so quickly as her sisters, she could achieve. The staff at the State school thought she could make greater strides by living in a home environment where she could receive more individual attention and more stimulation.

Karen's parents who looked upon placement in the State school as terminal, were helped to look upon Karen with more realism. Fortunately, the community where they lived had begun special classes and Karen was brought home. She showed some problems in testing her parents' feelings, and had to be reassured she was wanted, and in her rivalry with her next older sister. Karen progressed in school and her father was especially proud of her achievement. Not all cases have such happy endings. Karen's parents, especially her mother, though disappointed in having a retarded child, had given loving care to Karen in her early years or she could not have withstood the separation trauma from the family and responded to the institutional setting as well as she did.

Since Seguin's establishment of his private school in 1837, much progress has been made in education, and many communities have day classes for the trainable, as well as the educable. For older children and adults, the Federal government has recognized the need for vocational counseling and training for the mentally retarded through its program of Vocational Rehabilitation. Special education is essential for most of these children. However, others need additional help in order to take advantage of available education.

Although great strides have been made in the education of the mentally handicapped, less stress has been placed upon the emotional factors involved in the problems of learning. Yet, the mentally retarded child cannot make maximum use of his ability unless he is evaluated in his totality, including appraisal of his personality, as well as his intellect. Recently two psychologists compiled a number of papers under the title of "Counseling and Psychotherapy with the Mentally Retarded." This book discusses the possibilities of psychological treatment of the mentally retarded. The authors point out that "While much progress has been made toward demonstrating the value of psychotherapy with retardates, considerably more systematic research is needed before various theoretical implications can be adequately clarified."

With a large proportion of the children of school age sent to State Schools, the problem is not one of mental retardation alone, but of mental retardation along with emotional disturbance. These children have frequently been excluded from school because of behavior. They are described as destructive, unmanageable, restless, aggressive "bullies." They have become problems to the community because of the same forces that cause acting-out and rebellion in other children. There has been a tendency on the part of professional workers to regard the mentally retarded as quite different from persons of normal intelligence. Seemingly, because they are lacking in intelligence according to standardized tests, they are frequently considered lacking in emotions. Yet, any professional worker in close contact with children and adults diagnosed as mentally retarded is aware that they have feelings of hate, anger, and rage, and that they are very sensitive to the attitudes of others toward them. These feelings influence their achievment and behavior

just as they affect the performance and conduct of normal children. Much more research is needed on the relationship of intelligence to emotional growth. The mentally retarded are generally believed to have certain characteristics--rigidity, lack of judgment, and some specific defensive reactions contrived to cushion feelings of inadequacy. However, much more can and ought to be learned about the personality structures of high-grade mental defectives. It is the same as other children.

Jim is illustrative of an adolescent, retarded boy committing delinquent acts in the community--stealing, attacking younger children, etc. Over a period of five years, Jim consistently scored in the 60's on intelligence tests. The Child Guidance Clinic recommended commitment. On advice of their minister, his parents arranged for his placement at the State School when he was fourteen years old. Jim was an only child and lived with his parents in a large apartment building, located in a middle-class, residential neighborhood where the parents were active members at the nearby church. His mother said he looked "dopey". He was fat and spoke in a sing-song manner. Jim's frequent aggressiveness towards younger children greatly embarrassed his parents. They feared he might commit a violent act. While Jim was in the protective setting of the State School, his adjustment was considered very satisfactory. His test scores at the School indicated he has much more ability than he had shown prior to commitment. Jim was described as an emotionally immature adolescent, but one who might function with average intellectual capacity, showing ividences of a neurotic behavior pattern. His greatest conflict was his confusion about his sexual identity.

When Jim was released to the community, his mother phoned the social worker frequently for advice about handling him--whether to permit him to attend shows, to work, etc. An active treatment program was planned with Jim while his parents were counseled. With Jim, the emphasis was upon building his relationships with men. Thus, he was introduced to the woodshop program in charge of a permissive fatherly figure, an occupational therapist, at the Mental Health Centers. Jim later obtained a job as a stock clerk where he was supervised by a kindly man. Since Jim was not a verbalist, he found it easier to develop a relationship with the occupational therapist through this activity. The therapist represented an ego ideal and Jim identified with him--thus developing self-esteem, and self-confidence. The treatment was aimed to provide him with a corrective emotional experience.

In the meantime, the social worker was working with the parents, and the father was helped to assume a more active role in the family. Then the mother indicated she felt involved in Jim's problems and requested regular appointments. In the initial phase of the relationship, she intellectualized and resisted discussing meaningful material. After she felt more comfortable in the relationship, she learned that Jim could achieve academically within limits and that his behavior was not necessarily a reflection of his retarded intelligence--rather it was a reflection of a disturbance in his emotional growth. She gained some awareness of her relationship to Jim and believed she was infantilizing him and not permitting him to grow. After partially discussing some of her personal problems and recognizing how her own childhood experiences affected her handling of Jim, she decided she would be happier if she developed outside interests and did not focus all her time on Jim. Because of some of the emotional limitations of the mother, the worker focused on strengthening the ego, offering support, etc. rather than uncovering.

Jim has continually been employed and attended night classes at a vocational high school, and now has completed the second year. He believes he has reached his limit. At his church, he serves as an usher and is just beginning to develop friendships with young people. For if Jim was to hold on to the gains he made at the institution, it was necessary to involve his parents in the total treatment plan.

Here in Illinois, we have been impressed with the fact that children who test retarded at the time of commitment will often score in the dull-normal range upon return to the community and in response to treatment. It can well be assumed that these children at the time of their commitment were pseudo-mental defectives rather than mental retardates. We question if this was true mental retardation or functional mental retardation? This is why it is important for professional people to have some knowledge of the psychopathology of mental defect and the inhibition of intelligence. There are many other factors that affect this lower intelligence quotient, such as socio-economic conditions, cultural backgrounds--especially the impact of urban society, upon rural folk ways, emotional deprivation, neurotic interaction within families. This is why although frequently less verbal than children of normal intelligence, some mentally retarded can benefit from a therapeutic relationship. Children and adults classified as high-grade mental defectives have been found amenable to treatment. The attitude of the therapist, however, can influence the course of treatment.

Any program that will effectively meet the needs of all mentally retarded children must of necessity involve the skills of many trained personnel. Only in this way can the mentally retarded have a decent and useful role in our ever changing society, and in consequence not become totally dependent. For diagnostic and treatment purposes, there must be experts from many disciplines--psychiatrists, neurologists, psychologists, educators, social workers, speech therapists, vocational counselor, industrial and group therapists, to mention a few. Since for so long the retarded have been neglected for therapeutic consideration, for a time in many communities there will perhaps have to be special agencies and clinics for them. Yet existing agencies, such as Family Service and Child Guidance Clinics should be encouraged to extend services to the mentally retarded.

To assist the existing agencies in using and applying their skills to the mentally retarded, new orientation will have to be instituted and special community resources developed, such as day nurseries, social centers, sheltered homes for older adults, sheltered work shops, vocational training, residential and day schools and halfway houses. State Schools will care for the totally dependent and offer training and treatment to the moderately and mildly retarded. Placement in the institution should be considered one step in the total treatment for the child. Only at certain ages and under certain circumstances should these children be in residential schools for training, after which they should be returned to the community, and later some will return to the schools.

Our aim for the mentally retarded child must remain the same as set forth in the 1930 White House Conference that recognized the rights of the child as the first rights of citizenship, and pledged:

> "For the child who is mentally handicapped such measures as will early discover and diagnose his handicap, provide care and treatment, and so train him that he may become an asset to society rather than a Liability. Expenses of these services should be borne publicly where they cannot be privately met."

With our changing attitudes, may the mentally retarded develop feelings of adequacy and become participating members of society within their capacities.

PROSPECTS FOR PREVENTION

Benjamin Pasamanick, M.D.

I am going to begin at the end by sticking my neck out just as far as it can go and say that it is my firm belief, with some data to support it, that if we did everything that we could possibly do today, that if we did everything that we knew what to do today, we could probably prevent at least one half of the cases of mental defect and mental retardation that we know will occur. Actually I am probably being a bit conservative when I state that it is only a half. Like most chronic disorders, mental subnormality is heavily involved in the economic social cultural level and, therefore, to make changes, major efforts will have to take place and I leave the discussion for the actual methods in the hands of Dr. Douglas. I have already done it once before today and before I end, I hope to do it again.

You have undoubtedly had discussed, a number of the less frequent, as a matter of fact, rather uncommon and rare genetic disorders in which some very exciting work has been done. I have no intention of going into them in any detail but the prospects are really most dramatic. In such conditions, for instance as phenlypednuria we can think not only of preventing the mental defect but in a sizeable proportion of the cases, not all of them by any matter of means, but in a sizeable proportion, we can even now contemplate identifying the heterozygous carriers of the trait and by informing them, possibly either prevent marriage or think of preventing the occurance of defective children.

The same kind of thing we can talk about in such things as galactosemia perhaps where we now have quite obvious preventive measures in the RH and other blood sensitivities where with exchange transfusions we can effect significant preventive defects. We knew how to identify the carriers of these traits some time ago. How much was done to prevent the occurance of defect is another matter. It is not really these uncommon conditions that I want to concentrate on. Despite the fact that they are so dramatic and do get into the scientific literature in newspapers, they make up a relatively unimportant proportion of the tremendous numbers of defective and retarded children.

It is the large number of brain injured children, the large number of socio-culturally retarded children that I would like to concentrate on. Here is where prevention will play enormous effects if we can get them going. I think I might just mention the ground rules of what I am discussing. I would like to make differentiation, and I hope somebody has before, between mental retardation and mental defect both, as they constitute mental subnormality, mental defect I refer to as defect in the brain, retardation obviously is nothing more than slowing down from a potential which is present.

Now I would like to spend the rest of what time I have in describing a number of our studies which fit into a pattern, a large number of studies, some of them done by people right in this room. The number of studies in this area is now so large and so convincing that it would take a master magician to throw them out. The direction of most of the studies in intellectual potential and intellectual functioning are pretty much in one direction now. I hope that Dr. Skeels, who is sitting here and who has been a pioneer in this area, discussed this direction when he spoke.

About 12 or 13 years ago we began a study of the longitudinal development of negro infants. We have followed these children,for at least the last examination which was some time ago, for seven years and to make a long story short what we found simply was this. During our infant examinations in the group of children born in New Haven in 1943 we found that contrary to previous reports about development of negro children, that this particular group of children were developing no differently than the white groups of children that we were following at the same time. When we looked into the data to find out what possible reasons we could attribute this to, only one thing turned up.

We looked at the educational background of the parents, the housing, the number of children they had, the color of these children and at any number of things. But the only thing we found that was different from previous reports was the fact that these children weighed at birth just the same as white children did. Their birth length was the same and as they grew their weight and heights followed white curves. We made the hypothesis that what had happened was that due to wartime conditions, rationing and jobs, etc., that the mothers of these children had had an adequate diet. This normal development continued all the way up to our seven year examination. We could not distinguish or detect any major differences between these children and white children. There were a couple of relatively minor differences. First, we found that their language behavior was dropping as they got older and then when we analyzed the data we found that their language comprehension remained the same as white children but their verbal responsiveness had dropped and we attributed this to the fact that these children were being examined by white examiners. Actually at the age of seven we had them examined by negro examiners and we did not have this difficulty. Another distinguishing characteristic was that they were accelerated in motor ability. This has been attributed by some people to the possibility that they were closer to other primates. We found that they were accelerated. We did some further studies and found that this may very well be due to greater permissiveness in lower socioeconomic class negro mothers. However, we have done another study on this on a much larger group of negro and white children and in children born in the fifties there is no difference between negro and white children at all. They are all accelerated and I think this is due largely to better care.

On the basis of this hypothesis, that there was an effect during prenatal life on the fetus and fact that we knew from many other studies that brain injury occuring during pregnancy accounted for the largest number of children who were aborted or were stillborn or who died soon after deliver, we hypothesized again that these must be children who did not die but who went on to live and to develop a number of neuropsychiatric disorders caused by poor integration and disorganization in the brain. It has been known for some time that these still births, abortions, etc., are associated with complications of pregnancy and prematurity. Beginning some time in the fifties we began a series of studies in which we picked up the population exhibiting one neuropsychiatric disorder after another, went to the birth certificate registry, got all the information on that child from the birth certificate, then took the next child born to a mother of the same race, of the same age, the child being of the same sex, born from the same hospital at the same time as a control, then went to the hospital and got the obstetric records, the pre-natal records on both and got all the pertinent information on the new natal course, the pregnancey course, the delivery, etc., and then just made comparisons.

There are some seven different entities that we have in this way investigated. We have studied first, quite obviously, mental deficiency, epilepsy, cerebral palsy, behavior disorders in children, tics in children, reading disorders and speech disorders. In all these conditions except speech disorders we have found a significant association with complications of pregnancy and prematurity. The strength of the association varies with what each of us would consider the seriousness of the condition. We found the greatest association with cerebral palsy. Obviously the next one was epilepsy, mental deficiency, behavior disorders, reading disorders, tics and speech disorders last.

These are such interesting findings in the study of the mental deficiencies that we investigated that we found that the negroes, when we examined the associations of complications of pregnancy and prematurity, were significantly different between experimental control groups as far as prematurity was concerned. We had found the same thing in epilepsy and could attribute in epilepsy probably to the fact that there is more post natal injury, however, in mental deficiency we went a bit further and divided the cases up into I. Q. of 50 and below, and I. Q. 50 and above. When we did that, the findings were very striking. Under I. Q. 50, 93% of the negro children with mental defect had one or more complications of pregnancy on their background, whereas, above I. Q. 50 were heavily deluded by sociocultural retardation and not brain injury.

We went on to study the epidemology of prematurity and complications of pregnancy themselves as far as their relationship to socioeconomic status were concerned. It has been known for a long time by all obstetricians that we get much more prematurity and complications of pregnancy in lower socioeconomic classes so that our studies are not really new but they are just confirmatory. The data themselves are quite striking. For instance when we study prematurity by class, by socioeconomic differentiation, when we compare the upper economic fifth in whites with the lower economic fifth in whites, we find 5% of prematurity in upper and 8% in the lower. This is very significant statistically. However, when we go on to negroes the rate climbs to 14% When we look at complications of pregnancy in the same way we find about 5% in the upper fifth and climbs up to 14% in the lower fifth of whites and then jumps up to 50% in the negroes. What the specific factors involved are, we do not precisely know. There is a good deal of evidence for instance, as far as toxemia of pregnancy and prematurity are concerned, that nutritional factors play an important role. It has been shown that you can cut down enormously the rate of prematurity and toxemias of pregnancy by adequate feeding of protein.

We have done a little interesting kind of investigation there to indicate that we get more mental defect in children who are conceived in the summertime as contrasted to those conceived in wintertime. Actually this difference holds up only when you look at hotter summers as in contrast to cooler summers. In the hotter summers, or following hotter summers, we have a significant increase in children born with a mental defect. I think what may have happened there is that the intake of protein is cut down during hot weather and we get the effect on the child. By the way we look at complications of pregnancy by season of birth, exactly the same relationship is found particularly in toxemias of pregnancy and in bleeding during pregnancy.

What I have been telling you so far has been on the basis of retrospective studies except for that early negro study I told you about. These may be largely associations

rather than cause and effect. We cannot do experimental studies, obviously, on humans in this relationship. The best we can do is do the prospective longitudinal studies that I spoke of.

Starting in 1951 we began a study of the behavioral development of premature born children as contrasted to full term children. I will not go into detail on the methodology of the study but we took a sample of 500 children, prematurely born in Baltimore in 1952, and matched them for sex, race, socioeconomic status, age of mother, etc., and have been following them. In brief we found precisely what we expected. The rate of mental defect is higher in the prematurely born children. But more important, the whole intellectual range is skewed down starting from the top of the curve all the way down to the bottom, skewed in the downward direction in the prematures as contrasted to the full term controls.

This relationship is most true for the lightest babies, in other words the most premature. Because we got this sizeable sample of Baltimore babies, by making various adjustments for their distribution in the population, we were able to project this on the total population of infants born in Baltimore to give us some concept of the total intellectual potential in this group of infants. I ought to tell you too, that we have followed these children and re-examined them. Now at the age of three they have all been seen and the correlation between the early and late examination is surprisingly good in view of the fact that this period is one of extremely rapid development so that two years down in early childhood is equivalent to possibly ten years later and because of changes that have obviously occured in this group of children.

I would like to show a table of distribution first. I want to point out that what we are comparing here is our Baltimore infants with two groups of school age children. One group examined in Scotland at about 11 years of age and the group of children on whom the Stanford-Binet test was done. Here at this level of quotient 75 in our infants we have 1.4% in contrast to about 5% in this group of school age children. When we go up to quotient 85 this still remains quite low at 1.8% here. However, it has now risen in the school age children to about 14 and 1/2 percent.

I think I can show more clearly on the curves that we projected. You can see that this red curve here which is our Baltimore infants (this is all 40 weeks of age), exhibits a quite narrow range but the school age children have spread out. At three years of age our curve is also beginning to spread out someplace around here. What has happened is that the negro children and lower class whites have gone down to this direction and the upper class have gone up. This range, as far as I am concerned, is largely a range of sociocultural retardation and or plus the effect of the specific items that we used in testing, at 49 weeks of age we could find no significant difference between our negro and white children. At three years of age there is already a significant difference between the lower socioeconomic whites and the upper socioeconomic whites which did not exist at the 40 weeks of age.

The mean quotient for the negro children at three years of age is about 99. plus, it has gone up to 110 in the white children. I think we can predict on the basis of previous experience that the score is going to continue to go down in the negro and lower class whites and continue to go up in the upper class whites. What does this mean as far as prevention is concerned? I do not think I need to labor the point as far as our findings on complications of pregnancy, as far as our findings on prematurity are concerned, as far as our findings on what I think to be sociocultural

retardation are concerned, that a good deal of the causation just hits us between the eyes. What has to be done as a consequence is really not for me to say. I think this is something we might leave for Dr. Douglas from the Department of Health, Education and Welfare, to discuss.

I think this is part of the basis in my maintaining that if we did everything that we could possibly do, of what we already know at this time, that at least half of our cases of mental defect and mental retardation could be prevented and possibly in time this percentage could be increased.

TABLE I

Distribution of Intelligence Quotients reported in Literature Compared to Distribution of General Developmental Quotients in Baltimore Infants (1952)

Quotient	Baltimore Infants	MacMeekan (Scotland)	Stanford Binet
35	0.1	0.0	0.0
35-44	0.1	0.2	0.4
45-54	0.2	0.9	0.9
55-64	0.9	1.8	2.2
65-74	1.4	4.5	5.4
75-84	1.8	14.4	14.4
85-94	9.6	39.6	33.6
95-104	54.6	66.1	56.7
105-114	88.7	83.6	78.1
115-124	96.7	93.0	90.9
125-134	98.6	97.5	96.2
135-144	99.6	99.3	98.1
145-154	99.8	99.7	98.7
155-164	99.8	99.9	99.3
165-174	99.8	99.9	99.8
175+	99.8	99.9	100.2
Unknown	100.1	99.9	100.2

TABLE II

Distribution of General Developmental Quotients in Baltimore Infant Population (1952) Adjusted for Birth Weight, Race, and Economic Status

General Developmental Quotient	White	Non-White	Total	Cumulative
15-19	-	0.0	0.0	0.0
20-24	-	-	-	0.0
25-29	-	0.4	0.1	0.1
30-34	-	-	-	0.1
35-39	-	-	-	0.1
40-44	-	0.1	0.0	0.1
45-49	-	-	-	0.1
50-54	-	0.4	0.1	0.2
55-59	-	0.0	0.0	0.2
60-64	0.7	0.6	0.7	0.9
65-69	-	0.0	0.0	0.9
70-74	0.7	0.1	0.5	1.4
75-79	0.0	0.4	0.1	1.5
80-84	0.1	0.8	0.3	1.8
85-89	0.7	1.4	0.9	2.7
90-94	6.5	7.9	6.9	9.6
95-99	18.6	18.2	18.5	28.1
100-104	27.2	24.6	26.5	54.6
105-109	25.2	19.9	23.8	78.4
110-114	9.0	13.9	10.3	88.7
115-119	5.2	3.9	4.9	93.6
120-124	3.0	3.4	3.1	96.7
125-129	0.7	2.1	1.1	97.8
130-134	0.7	1.0	0.8	98.6
135-139	0.4	0.4	0.4	99.0
140-144	0.7	0.4	0.6	99.6
145-149	0.3	-	0.2	99.8
Unknown	0.4	0.0	0.3	100.1
Total	100.1	99.9	100.1	100.1

SOME PROGRAM DIRECTIONS IN THE FIELD OF MENTAL RETARDATION

Joseph H. Douglass, Ph.D.
Program Coordination Officer
Office of the Secretary
U. S. Department of
Health, Education, and Welfare

As Chairman of the Department's Committee on Mental Retardation, I am delighted to have this opportunity to speak to you in reference to the continuing activities of the U. S. Department of Health, Education, and Welfare in the field of mental retardation.

As the Department is sometimes referred to as the "Department of Human Resources", it is recognized that it has large responsibilities in this field. Basically, in conjunction with its regular programs, and limited only by the statutory authority of its agencies, the Department has responsibility to utilize its resources in cooperation with the States and local communities in the prevention and amelioration of the problems of the mentally retarded in the Nation. Its efforts, which in financial terms amount to around $7 million per year, are intended to help improve and increase services at the family and community level for mentally handicapped individuals and to mobilize resources for the continued impovement of the attitudes of society generally toward this group. It is evident that from many standpoints, not only is there far too little known about the extent and nature of the problems involved on either a national or community basis, but perhaps most importantly, that knowledge which is available is not being applied on a wide enough scale.

Quite briefly, the general program directions of the work undertaken by the agencies of the Department in approaching the problems are as follows: The Public Health Service's Institutes of Mental Health and Neurological Diseases and Blindness are engaged in numerous activities in the areas of research on the etiology, diagnosis, treatment, and prevention of relevant neurological diseases and psychological disorders, and in the area of training of medical and supporting personnel.

Activities of the Children's Bureau of the Social Security Administration consist of fact-finding, consultation, and grants-in-aid to State agencies which assist in developing programs focused primarily on infants and younger children. The range of State and local activities which utilize funds includes assistance in the development of special centers for diagnosis, treatment, and follow-up services; social case work; services in the home such as counceling parents regarding early child training; planning for institutional care and the improvement of such care; and placement in foster family homes, day care center, and nursery schools; evaluative studies and research in these fields.

The emphasis of the Bureau of Public Assistance of the Social Security Administration is upon the consultative services to States on program plans for essential social services and staff training, participation in community organization plans and demonstration projects, and research. In categorical programs for the needy administered by the Bureau, assistance is provided to eligible mentally retarded individuals through medical care and money payments.

The Bureau of Old-Age and Survivors Insurance is promoting public awareness of the benefit provisions for mentally retarded children under the disability program, and is cooperating with other programs which serve them.

The 1956 amendments to the Social Security Act extended disability protection under the old-age and survivors insurance program to include benefits for dependent disabled children aged 18 or over who have been continuously disabled since before they reached age 18. For the purposes of these benefits, disability may have been caused by injury, bodily sickness, mental illness, or blindness-- a condition that can be medically determined.

Preliminary data on operations under the childhood disability benefit provisions of the Social Security Act reveal that two diagnostic groups accounted for more than 80 percent of the children found disabled: (a) diseases of the nervous system and sense organs, 43 percent; and (b) mental, psychoneurotic, and personality disorders, 41 percent. For children found disabled the primary diagnoses occurring most often were, mental deficiency, 15 percent; cerebral spastic infantile paralysis with mental deficiency, 15 percent; cerebral spastic infantile paralysis, 15 percent; and epilepsy with mental deficiency, 4 percent. Together, these 4 specific conditions accounted for more than 7 out of 10 of the children found disabled. Some degree of mental deficiency was present in about 2 out of 3 of the children found disabled either as the primary diagnosis or as a residual of the primary diagnosis. In many of these cases, the mental deficiency was associated with cerebral palsy or epilepsy.

To turn to the Office of Vocational Rehabilitation, its efforts are in the area of leadership, research, the training of professional personnel, and technical and financial assistance to States and other public and voluntary organizations, to increase and improve vocational rehabilitation services to the mentally retarded who are approaching and who are of employable age.

The office of Education has a program for exceptional children and youth which includes the mentally retarded. The programs include the collection and dissemination of information, the conduct of studies, and consultation particularly to State departments of education, national organizations, colleges and universities, to other government agencies and to individuals.

Thus the activities of the Department cover a broad area of etiology, nosology, diagnosis, treatment and prevention of neurological and psychological disorders; the dissemination of results of research, the training of medical and supporting personnel; broad-scale research, and services to the States and communities in the utilization of existing and developing knowledge in the care, treatment, education, social service, and vocational rehabilitation of the retarded. Grouped together, all of the activities of the Department can be classified under broad headings of research and demonstrations, training and services.

The Department observes the general principle that, wherever possible, existing services should be expanded and developed to meet the needs of the handicapped. As for example, that the health program for the mentally retarded should form an integral part of public health and medical services. Its development to large extent must stem from the existing general services including maternal and child health, school health, and mental health services. Use should be made of the administrative machinery of those services and research activities should be part of the total research program in child development.

The same principle applies in the field of education. Schools or classes for the mentally retarded should be organized as part of the general school program.

Similar considerations apply to welfare services and to vocational training and guidance, as the efforts at early diagnosis, care, and education may be largely wasted if provisions are not made for the social and economic adjustment of the mentally handicapped when they reach adolescence and adulthood.

The research and other projects currently being supported by the several agencies of the Department present an impressive array. There are 46 projects in process under the cooperative research program of the Office of Education. These projects, among others, are concerned with such topics as, specialized educational methodology, educational terminology, comparative studies on learning characteristics, articulatory development and phonetic perception, perception of symbols in skill learning, conditions influencing insight and problem-solving behavior, effects of group training, and tests of social adequacy. According to progress reports, 39 of the investigators are drawing all or part of their samples from public school systems, and 21 from residential schools. In addition, at least 12 studies report the cooperation of other community agencies as sources of children. Thus it appears that hundreds of persons not on the research staffs are contributing to these investigations and thousands of children are involved.

Projects of the National Institutes of Mental Health and Neurological Diseases and Blindness cover a wide range of investigations into genetics and heredity, neurology, biochemistry, metabolism, psychological development, hearing loss, play patterns, ability structure and differential diagnosis, among other fields. Other projects being supported, concerned mainly with training of personnel, relate to problems of training of neurologists, pediatricians, social workers, psychiatrists, play therapists and clinical psychologists.

Currently the two Institutes are supporting some 25 or more projects with relevance to the field. Studies include, as examples, those concerned with metabolism and functioning of the living brain, blood-brain barrier studies, neurol correlates of mental activity and behavior, localization of psychological functions in the brain, neuropathological lesions in mental deficiencies, and etiology of perinatal brain damage, among others. As nearby examples, a study is currently being conducted by Messrs. Reitan and Heimburger relative to psychological measurements related to brain lesions at the Medical Center of Indiana University. Also, Frances Graham at the University of Wisconsin is currently engaged in a psychological study of brain-injured children.

Grants in the amount of $1,300,000 have been made available by the Children's Bureau in the current year to the health departments of some 30 States for special demonstration projects. A grant to the State of Tennessee, as an example, is helping to provide diagnostic and therapeutic services for mentally retarded children in the Midsouth area, covering western Tennessee, Southeastern Missouri, Eastern Arkansas and Northern Mississippi. Under this project conditions of the children are being evaluated and findings being referred to the physicians in their home communities. The intensive follow-up in the Memphis area includes both individual and group parent counseling, speech therapy, hospital facilities and work with the Department of Public Health, Nursing Division, the Department of Public Welfare, Child Welfare Division, and the Family Service of Memphis. Nearby examples of projects supported by funds provided by the Children's Bureau are

in Illinois, Michigan and Wisconsin. The Illinois special project being supported with Maternal and Child Health funds in the amount of $44,500 is for the establishment of a special clinic at Children's Memorial Hospital in Chicago in the effort to demonstrate the type of care and follow-up services which can be given to mentally retarded children and their families within the community. Emphasis in the project is upon early case-finding among infants and pre-school children. The project also will provide demonstration and educational facilities for professional workers in the field of mental retardation.

With $34,500 Maternal and Child Health funds, a training project has been set up as a part of the pediatric department in the medical school at the University of Michigan, its purpose being the training of residents, medical students, and others in the diagnosis and treatment of mentally retarded children. In order for the trainees to learn about the community as well as the clinical aspects of care of these children, a small group of children living around Ann Arbor will receive intensive follow-up service.

The Children's Bureau also has made available $30,000 for a training program at the University of Wisconsin Medical School at Madison. The primary purpose of the project is to train residents, medical students and others in the diagnosis and treatment of mentally retarded children. Under the project, children from all over the State will be accepted for diagnosis and evaluation, and the staff of the State Health Department will attempt to provide follow-up services to these children in their own communities.

The Division of Social Services of the Children's Bureau has been concerned with extending and improving basic child welfare services to retarded children of all ages. These services include foster home care, boarding care, day care, homemaker services and counseling with parents regarding problems of social adjustment. In order to provide effective services for this group, the Division is offering consultation to States in staff development and community planning for social welfare services and is working with professional schools for the development of instructional material to better equip students for work in this field.

Although there are no earmarked funds for mental retardation in the grant-in-aid program to States for child welfare services, regularly apportioned funds are being used in various ways to improve services and to finance training institutes. In February 1958, the Children's Bureau, in cooperation with the Division of Mental Hygiene in Ohio, sponsored a training institute for child welfare supervisors in Region V. The Children's Bureau is assuming leadership in strengthening the contribution of public health nurses, child welfare workers and related personnel through workshops and institutes of this kind and other staff development techniques. Voluntary agencies, national organizations and professional schools of social work are cooperating in these efforts.

The Office of Vocational Rehabilitation through its basic program and a variety of grant categories is seeking to increase the number of mentally retarded persons rehabilitated annually from a level of about 500 in 1955 to approximately 1500 in 1959. In 1957, State vocational rehabilitation agencies under the basic support program rehabilitated into gainful employment 1,094 mentally retarded persons.

The mentally retarded are among the more difficult cases to rehabilitate as a result of a variety of factors and circumstances. Some of these are the lack of specialized facilities for their work evaluation and preparation, and resistance

to their employment because of lack of public and employer understanding of the many jobs they can perform successfully. The Office of Vocational Rehabilitation has been making a direct nation-wide attack on these complex problems under basic support grants, extension and improvement grants, expansion grants, training authority, research grants and the program of selected demonstration projects which was inaugurated during this current fiscal year. As a direct result of these and other activities, very substantial progress has been made and is being made in the total rehabilitation work with the mentally retarded. As indicated, it is anticipated that State vocational rehabilitation agencies will rehabilitate into gainful employment under their basic support programs 1,250, mentally retarded persons in fiscal year 1958, and 1,500 such persons in 1959.

Two research projects that were conducted in 1957, are in operation in 1958 and will be continued in 1959. Both of these projects are doing fundamental research in factors affecting the employability of the mentally retarded. Out of these two research projects there have been developed in 1958 ten selected demonstration projects (occupational centers for the mentally retarded) designed to apply improved rehabilitation methods and techniques to the mentally retarded. These ten projects, located in the various parts of the country will continue in 1959.

State vocational rehabilitation agencies under their basic support program and in Extension and Improvement projects for the mentally retarded will spend almost three-quarters of a million dollars in 1959 in the rehabilitation of the mentally retarded who are of working age. The Office of Vocational Rehabilitation will conduct special service training courses in 1959 for vocational rehabilitation counselors in work with the mentally retarded. These courses are in addition to the many training programs it supports for the training of personnel in all phases of rehabilitation.

Whereas it may be far too early to evaluate the effectiveness and value of the several activities and programs embraced under the umbrella of the programs of the Department of Health, Education, and Welfare in this field, I think, nevertheless we may agree that a significant impact is being made on the States, communities, voluntary organizations, and individual investigators through the joint efforts of the several programs which now have been focused on this sector of our population.

It is unnecessary to point out that in recent years in one dramatic advance after another many infectious diseases have been virtually conquered, infant and maternal mortality have been dramatically decreased, and our physical environment has been made safer and more healthful. Whereas this progress presents certain problems in the field of subnormality as a result of the fact that many infants now live who otherwise might have died, the challenges to find as rapidly as possible improved techniques of prevention and vastly improved methods of treatment and care of mental handicaps are increased.

There is increasing evidence that the challenges presented will be met as the growing and rapid progress being made in medicine, methods of social welfare, and educational methodology, among other fields, attest.

In recent years, it has become increasingly evident that the problems can best be met through the team approach--team meaning the combined efforts and resources of many disciplines, lay persons, voluntary organizations, and the several levels of government by which our Nation is characterized.

Agreement seems to be further that an adequate community program must include sufficient staff and facilities, and on a coordinated basis should provide diagnostic and treatment centers; social services for the family; and adequate educational program, vocational rehabilitation, guidance, and employment services, including sheltered workshops; and facilities for recreation and leisure-time activities. In addition, for the severely subnormal, each community should have access to centers for their residential care and treatment, and provisions for after-care on an out-patient basis for those released. The accomplishment and success of these services in the final analysis will depend upon the action programs of persons on the community level in bringing them to pass.

Currently available from the Department, but in very limited number, are two mimeographed reports which describe in greater detail the data which I have presented today. These reports are entitled Mental Retardation--Programs and Services of the U. S. Department of Health, Education, and Welfare, Fiscal Year 1959, and Research and Other Projects in Mental Retardation Currently Being Financially Supported or Assisted by Operating Agencies of the U. S. Department of Health, Education, and Welfare.

CLOSING COMMENT

James F. Maddux, M.D.

There are two real brief things I want to say. One, this conference had two objectives.

1. To try to present a quick rundown on new knowledge in the area of mental retardation, of research, services., etc.

2. Permitting important workers in state programs to get together and exchange information about the problems they are working on and to consider mutual concerns.

Each of us has some notion for himself as to how well those two objectives were achieved.

The second thing I wanted to say was that I have never worked primarily in the field of mental retardation and have in view of this, felt a little like an outsider and sympathetic supporter for the people who are working full time in the field. I think it might be worth while to comment that during the last five years it has been possible for an outsider to percieve a dramatic advance in this field. The extension of services and development of new facilities and in the clarification of some questions which have been more confused and vague in the past than they are now.

Meeting adjourned!

TUESDAY, MARCH 11, 1958

THEME - OVERVIEW - NATIONAL AND STATE

8:30 A. M. - REGISTRATION
9:30 A. M. - GENERAL SESSION

Chairman:	Mr. Willard L. Couch, Springfield
Welcome:	Otto L. Bettag, M.D., Springfield
A New View of An Old Problem	George S. Stevenson, M.D., New York

10:00 - RECESS
10:30 - GENERAL SESSION

Goals and Directions of State Programs for the Mentally Retarded	Illinois	- Otto L. Bettag, M.D.
	Indiana	- Stewart T. Ginsberg, M.D.
	Michigan	- Mr. Charles F. Wagg
	Ohio	- Joseph E. Duty, M.D.
	Wisconsin	- Leslie A. Osborn, M.D.

12:00 NOON - LUNCHEON CONFERENCES

A. Superintendents and Administrators	Host:	Mr. Willard L. Couch Springfield
B. Social Service	Hostess:	Miss Dorothea L. Dolan Chicago
C. Psychological Services	Hostess:	Phyllis Huffman, Ph.D. Chicago
D. Nursing Service	Hostess:	Miss Catherine A. Morgan, R.N. Chicago
E. Special Teaching & Training	Host:	Mr. Leon H. White Springfield
F. Vocational Rehabilitation	Host:	James F. Maddux, M.D. Chicago
G. Activity Programs	Hostess:	Miss Bertha Schlotter Chicago
H. Other Interest Groups	Hostess:	Margery J. Mack, Ph.D. Chicago

1:30 - 3:15 P.M. - DISCUSSION GROUP MEETINGS (CONCURRENT)

1. PLANNING THE STATE PROGRAMS (Goals, Problems, Designs, Operation)	NORTH ROOM
Discussant Leader:	Mr. Willard L. Couch, Springfield
Resource Persons:	George S. Stevenson, M.D., New York Miss Jane Bull, Chicago Mrs. Sadie E. Smith, Tampa 7, Florida
2. COMMUNITY SERVICES (Medical, Social, Educational, Vocational Programs)	SOUTH ROOM
Discussant Leader:	Miss Bess Craig, Chicago
Resource Persons:	Bernard Farber, Ph.D., Urbana Miss Ruth Williams, Chicago
3. THE INSTITUTION (Utilization by the Community, Programs, Administration)	CHICAGO ROOM
Discussant Leader:	Mr. Harvey A. Stevens, Madison 5, Wis.
Resource Persons:	Gale H. Walker, M.D., Polk, Pa. Harold M. Skeels, Ph.D., Bethesda, Md.
4. RESEARCH (Areas of need, Program Development, Problems of Design, Epidemiology)	MANOR ROOM
Discussant Leader:	Miss Gwen Andrew, Lansing, Mich.
Resource Person:	Thomas Gladwin, Ph.D., Bethesda, Md.

3:30 - 4:30 P.M. - GENERAL SESSION

Chairman:	Leslie A. Osborn, M.D., Madison, Wis.
Current Research in Mental Retardation - Cultural and Psychological	Thomas Gladwin, Ph.D., Bethesda, Md.
Biological	Stanley W. Wright, M.D., Los Angles

6:00 - 7:30 P.M. - SOCIAL HOUR - MANOR ROOM

Host: Otto L. Bettag, M.D., Director, Illinois Department of Public Welfare

WEDNESDAY, MARCH 12, 1958

THEME - INSTITUTIONAL - CARE

9:30 A. M. - GENERAL SESSION

Chairman: Stewart T. Ginsberg, M.D., Indianapolis

Future Role of the Institution — Gale H. Walker, M.D., Polk, Pa.

9:30 A.M.

Who Needs an Institution? — Bernard Farber, Ph.D., Urbana

10:00 A.M. - RECESS

10:30 A.M. - GROUP DISCUSSION MEETINGS

5. PLANNING THE STATE PROGRAM II — NORTH ROOM

6. COMMUNITY SERVICES II — SOUTH ROOM

7. THE INSTITUTION II — CHICAGO ROOM

8. RESEARCH II — MONOR ROOM

12:00 NOON - LUNCHEON

1:30 P.M. - GROUP DISCUSSION MEETINGS

9. TRANSITIONAL AND AFTERCARE SERVICE — NORTH ROOM

   Discussant Leader: Mrs. Margaret C. Weber, Chicago
   Resource Person: George S. Stevenson, M.D., New York

10. RECRUITMENT AND RETENTION OF STAFF — SOUTH ROOM

    Discussant Leader: Mr. Leon H. White, Springfield
    Resource Person: Gale H. Walker, M.D., Polk, Pa.

11. SPECIAL EDUCATION AND TRAINING — CHICAGO ROOM

    Discussant Leader: Mr. Ray Graham, Springfield
    Resource Person: Harold M. Skeels, Ph.D., Bethesda, Md.

12. PHYSICAL PLANT PROGRAMS	MANOR ROOM
Discussant Leader:	V. A. Stehman, M.D., Lansing, Mich.
Resource Person:	Mr. Ray L. Whitemer, Chicago
13. VOCATIONAL REHABILITATION	CASINO ROOM
Discussant Leader:	E. C. Cline, Ph.D., Springfield
Resource Person:	Bernard Farber, Ph.D., Urbana

4:00 P.M. - GENERAL SESSION

Chairman:	Joseph E. Duty, M.D., Columbus, Ohio
Preadmission, Release, and Aftercare Service	Mrs. Sadie E. Smith, Tampa 7, Fla.

THURSDAY, MARCH 13, 1958

THEME - COMMUNITY SERVICES

9:00 A.M. - GENERAL SESSION

Chairman:	Mr. Charles F. Wagg, Lansing, Mich.
Panel:	
Community Obligations for the Retarded	Moderator: James F. Maddux, M. D. Chicago
School Program	Roderick N. Purcell, Ph.D., Columbus
Community Clinics	Mrs. Annette A. Calloway, Chicago
Vocational Rehabilitation	Mr. O. T. Omlid, Mt. Pleasant, Mich.
Health Services	Verne K. Harvey, M.D., Indianopolis
Child Welfare	Miss Bess Craig, Chicago
Parent Groups	Mr. G. I. Wallace, Madison, Wis.

10:00 A. M. - BUZZ GROUPS

10:30 A.M. - RECESS

11:00 A. M. - PANEL: ANSWERING THE PRACTICAL QUESTIONS

12:00 NOON - LUNCHEON

Luncheon Chairman:	Harold M. Graning, M.D., Chicago
Social Role of the Mentally Retarded	Mrs. Ruth Williams, Chicago

1:15 P. M. - GENERAL SESSION

Chairman:	Mr. Melville H. Hosch, Chicago
Prospects for Prevention	Benjamin Pasamanick, M.D., Columbus

1:45 P. M.

What the Department of Health, Education and Welfare is Doing	Joseph H. Douglass, Ph. D., Washington, D. C.

2:15 P. M.

Closing Comment	James F. Maddux, M.D., Chicago

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Discover Mentally Retarded Often Can Be Self-Supporting

By Robert S. Kleckner

Public attitudes toward mental retardation are changing from ridicule to compassion, from hopelessness to open-mindedness.

And as a consequence, society is beginning to learn that many of the retarded do not need custodial care and can engage in self-supporting work.

Mrs. Ruth Williams, supervisor of the Chicago office of the Lincoln and Dixon state schools operated by the Illinois Department of Public Welfare, emphasized these points Thursday as she addressed the final session of the first regional Conference on Mental Retardation at the Hotel St. Clair.

The three-day meeting attracted some 75 experts from the Midwest and about 45 others from over the nation in discus-

Mrs. Williams said:

"Today the mentally retarded are not generally regarded as strange, weird beings to be shunned or isolated, but as individuals who have feelings and certain rights of happiness. All mentally retarded are not the same. They vary in abilities and talents."

Because of this variation, she continued, much can be accomplished with many who may be below normal intelligence. Mrs. Williams asserted:

"Traditionally Western European cultures have long made use of mentally retarded adults. When our nation was largely rural, many chores could be performed by the mentally retarded.

"Along with urbanization, as prejudices are being overcome

She made a plea for more accurate differential diagnosis so that treatment and training can be placed on an individualized basis.

Mrs. Williams also urged more research on the relationship of intelligence to emotions, suggesting that certain personality traits of the mentally retarded might be traced to frustrations because of the lack of acceptance of the person.

She said professional workers were aware that these individuals have feelings of fear and anger.

"These feelings," she added, "influence their achievement just as they affect the performance and conduct of children with normal intelligence."

The conference was sponsored by the Illinois Department of Public Welfare and the U.S.

Probe Deeper Into Nutrition, Mental Function Link

By Robert S. Kleckner

More and more research, with some positive results already is going into the relationship of nutrition and metabolism to mental retardation.

Dr. Stanley W. Wright, pediatrician at the University of California Medical Center, Los Angeles, outlined some of the work as he addressed the Conference on Mental Retardation at the St. Clair Hotel.

Recent Effort

Dr. Wright said that studies already have indicated that in about 3 per cent of the cases there were biochemical aspects.

Only in the last few years have those concerned with mental deficiency branched into detailed research seeking a possible link between foods and their utilization by the body, as well as hormonal functions and certain mental states.

As a result, specific diets have been used to control and improve some of the cases.

Preliminary research has provided evidence, he continued, that biochemistry likely will have a growing importance in prevention and treatment of some mental ailments.

Dr. Gale H. Walker, superintendent of the Polk State School, Polk, Pa., said that on a national average institutions for the mentally retarded were 20 per cent overcrowded, all with long waiting lists.

In view of current tax loads and increased building costs, he foresees little likelihood in greatly reducing the bed space deficit.

Issue Of Care

Dr. Walker said "we have permitted the parents and public to convince us we should give a cradle-to-the-grave care to the mental defectives." He expressed the opinion this was unnecessary in many cases in which patients could be improved to where they could be cared for at home with frequent readmissions to the institutions for additional therapy. He admitted:

"This undoubtedly would mean additional responsibility upon the family and the community. To advocate such a radical program I am certain would produce severe resistance on the part of many families and most community agencies."

But he said he is certain that someday many of these conditions would be so amenable to treatment that many patients could be cared for at home with periodic examination and treatment at institutions.

The conference, ending Thursday, is sponsored by the Illinois Department of Public Welfare and the U.S. Public Health Service.

Decatur Review
March 12, 1958

Mental Illness Prevention Need Stressed

By O. T. Banton
Of the Herald and Review Staff

Chicago, March 12

Learning the causes and preventing mental disease will engage more attention of specialists in the mental health field, since providing proper care for all types of mental cases would bankrupt the public.

This is being made one of the points of emphasis at a five-state regional conference on mental retardation, which opened here Tuesday.

To cope with the cases now needing attention, much work has to be done at the community level, for institutional facilities "couldn't be built fast enough" to take care of them, experts who addressed the meeting Tuesday agreed.

About 125 persons are attending the conference.

2 Per Cent Retarded

Authorities estimate that 2 per cent of the population is mentally retarded and some put the figure as high as 4½ per cent, the meeting was told by Dr. George S. Stevenson, New York, consultant of the National Assn. for Mental Health.

The lower figure would give Illinois nearly 200,000 mentally retarded, or 20 times as many as are being cared for in their state's two institutions—the Lincoln State School and the Dixon State School where a total of 10,200 are housed. There are about 1,000 more in private institutions in the state, and 40 in security state hospital at Menard.

These patients range in age from infants to 92 years, and about 70 per cent are adults. One of Illinois' problems is caring for the babies, for which it has 700 beds. There are 590 babies on the waiting list at Lincoln and Dixon. Ohio solves this problem by accepting no mentally retarded patients under six years of age. This, the conference agreed, is not a good program.

CHICAGO SUN-TIMES, WEDNESDAY, MARCH 12, 1958

Charges 'Mentally Retarded' Label Sometimes Is Unjust

By Robert S. Kleckner

A lot of youngsters have been labeled mentally retarded without just cause, a representative of the National Institute of Mental Health asserted Tuesday.

Dr. Thomas Gladwin, psychologist and anthropologist from the Community Service Branch of the Institute, also maintained that present "intelligence" tests appear to be unreable in predicting social and occupational adequacy in many instances. "We need to make a new start" he said.

He was one of the speakers at the opening session of the nation's first Regional Conference on Mental Retardation Tuesday at the St. Clair Hotel. The Conference, lasting through Thursday, is sponsored by the

Dr. George S. Stevenson of New York addresses regional conference on mental retardation at St. Clair Hotel.

Southern Illinoisian
March 11, 1958

Kunce Delegate To Meeting On Retardation

Peyton Kunce, Jackson County Court judge and member of Gov. William G. Stratton's commission on mental retardation, will attend the first joint federal-regional conference on mental retardation.

Kunce also will represent unofficially the Egyptian Assn. for Mentally Retarded Children, of which he is president.

The regional conference, a five-state affair, opened today in Chicago and is to close Thursday. States participating are Illinois, Indiana, Michigan, Ohio, and Wisconsin.

Sponsors are the Illinois Dept. of Public Welfare and the U. S. Public Health Service.

Chairman for the opening session will be Willard L. Couch, deputy director of the state mental health service. Principal speaker Tuesday will be Dr. George S. Stevenson, consultant to the National Assn. for Mental Health, on the topic "A New View of an Old Problem."

Kunce expected to attend the final days of the session and to remain in Chicago Friday for a meet-

CHICAGO DAILY NEWS, Wed., March 12, '58 19

Don't Lock Up and Forget Retarded, Families Urged

BY ARTHUR J. SNIDER
Daily News Science Writer

Many families are urged by their physician to "institutionalize and forget" their mentally retarded child. But a Pennsylvania physician contends that's bad advice.

Dr. Gale H. Walker, superintendent of the Polk State School, Polk, Pa., said Wednesday close contact between

INSTITUTIONS have erred, Dr. Walker said, in permitting parents and the public "to con-

that institutions of the future must be organized so that they will handle patients rapidly, without long periods of time on waiting lists.

Instead of children being custodial wards of the state, they should be treated as patients — "medically, nutritionally, pschologically and educationally in a manner gen-

Chicago American
March 10, 1958

Clinic on Mental Health to Open Here Tomorrow

Chicago will be host to the nation's first regional conference on mental retardation, tomorrow through Thursday at the St. Clair Hotel, Dr. Otto L. Bettag, state welfare director, announced.

The conference, sponsored jointly by the Illinois Department of Public Welfare and the United States Public Health Service, will explore the problems of mental retardation at national, state and local levels.

Doctors and health and welfare officials from the Midwest and other areas will address the more than 120 delegates from Illinois, Indiana, Michigan, Ohio and Wisconsin.

DECATUR HERALD March 12, 1958

Local Effort Urged to Aid Retarded

By O. T. Banton
Of The Herald and Review Staff
Chicago, March 11

It would be impossible to build institutional facilities fast enough to take care of the mentally retarded children and adults who need special training and care. Much work in this field has to be handled in the home communities.

This was the concensus of about 125 mental health workers meeting was told by Dr. George S. Stevenson, New York, consultant of the National Assn. for Mental Health.

The lower figure would give Illinois nearly 200,000 mentally retarded, or 20 times as many as are being cared for in their state's two institutions — the Lincoln State School and the Dixon State School where a total of 10,200 are housed. There are about 1,000 more in private institutions in the state, and 40 in security state hospper cent.

Another 600 are in communi classes for the "trainables," tho with an IQ of 30 to 50 per cen There are 40 such classe but these are not available to chil ren over 16. A special class 30 who are over 16 is being co ducted at Hull House in Chica as a pilot project. The other classes are handled in church bas ments and other quarters than t public schools. Finding teache for them is reported to be dif

Chicago American - March 11, 1958

Retarded Child's Other Woe Told

Lack of brain power is not the only trouble confronting the mentally retarded child, according to a nationally known expert.

If the child's emotional problems could be cleared up he woud function better mentally, said Dr. George S. Stevenson, medical director of the National Association for Mental Health.

Addressing the nation's first regional conference on mental retardation, Dr. Stevenson pointed out that the retarded carry a heavy burden of emotional ills due to their lack of opportunity to develop normal social relationships within the family and community.

BELIEFS FAULTY

Dr. Stevenson said:

"This psychopathological element means that the old belief in untreatability must be modified because there are many factors in mental deficiency that are reversable.

"For this reason the tendency to set up special clinics for the mentally de-

to offer the mentally deficient."

The three-day meeting at the St. Clair Hotel is attended by 125 persons interested in plight of the mentally retarded, including 80 delegates from a five-state area.

Directors of state mental health programs in Indiana, Michigan, Ohio, Wisconsin and Illinois are taking part in the program.

DR. BETTAG TALKS

In a welcoming address, Dr. Otto L. Bettag, director of the Illinois Department of Public Welfare, declared:

"It is the goal of the conference to bring about improved services for mentally retarded persons in the Midwest by providing an exchange of ideas, problems and experience."

"Piece-meal planning" by the states and the practices of caring for "low-grade mentally deficient and high-grade misbehaving" in the same in-

Chicago Daily News - March 11, 1958

Urges Treatment For Retarded Kids

Mental Health Chief Calls Outcast Role a Trouble Source

The old belief that mental retardation is untreatable must be changed, a conference was told here Tuesday.

Dr. George S. Stevenson, medical director, National Association for Mental Health, New York, said there are "many factors in mental deficiency that are reversible."

He spoke to the Conference on Mental Retardation sponsored by the Illinois Department of Public Welfare in the St. Clair hotel.

* * *

A YOUNGSTER'S disability is only in part due to his mental deficiency, Dr. Stevenson said.

Because of his deviation, the child finds it difficult to establish the 'social relationships necessary for healthy development.

Thus, the tendency to set up special clinics for the mentally retarded may be a disadvantage," said Dr. Stevenson.

Instead, he said, mentally retarded youngsters could be treated at regular child guidance clinics where they would mix with normal children.

Purpose of the three-day conference, said Dr. Otto L. Bettag, state welfare director, is to bring about improved services for the mentally retarded by providing for an exchange of ideas, problems and experience.

DECATUR HERALD March 13, 1958

Mentally Retarded Boys Disrupt Family Life More Than Girls Do

By O. T. Banton
Of The Herald and Review Staff
Chicago, March 12

Mentally retarded boys are usually given preference over girls in admission to mental institutions.

The reason is that their presence in a home is more disruptive of the family relations than is the presence of a mentally retarded girl.

These are some of the findings in a three-year study completed last year by the Institute for Research on Exceptional Children at the University of Illinois. A report on the survey was given here today at a three-day conference on

outside the house."

The husband and wife relations were found more harmonious in cases where the retarded child was in an institution than if they were caring for it in the home, Dr. Farber said. In many instances the family relations were practically normal after the retarded child was removed from the household.

In cases where the mentally retarded child was being cared for at home, the wife's mother was found to be [illegible] help than her mother-in-law, [illegible] U of I psychologists reported.

Among admissions to the Lincoln State School from 1953 to 1955, Dr. Farber reported, the average age of the boys was 6.6 years and the girls 10.2 years and he believes this is fairly repre-

CHICAGO DAILY NEWS
6 ★ ★ ★ Thurs., March 13.

We're All Potential Geniuses

Most Brains Equal At Birth: Doctor

BY ARTHUR J. SNIDER
Daily News Science Writer

There isn't much difference between the brainpower inherited by an Einstein and a man on the street, a psychiatrist indicated here Thursday.

Most people, he said, come into this life with just about the same amount of native intelligence.

* * *

"**THE EVIDENCE** is far from complete, but there is a great deal of information presently available to support the view that the range of normal human intellectual potential is much narrower than has been thought," said Dr. Benjamin Pasamanick, professor of psychiatry, Ohio State University.

He spoke before a Conference on Mental Retardation in the St. Clair hotel.

* * *

WHAT differentiates an Einstein from the rest of us, said Dr. Pasamanick, is the sociocultural environment to which he is exposed.

Another possible factor, not yet well-defined, is the freedom of the genius from even a minimal amount of damage to the brain in the embryonic and birth stages.

Dr. Pasamanick implied that the price of gestation and birth may be the destruction through toxic or physical factors of a few of the millions of brain cells.

* * *

IN 97 or 98 per cent of the population, it is too few to be noticeable. It is only when the damage is great, as in the case of mentally retarded, that the condition becomes apparent.

Dr. Pasamanick pointed out that repeated studies have shown that "psycho-social factors seem to outweigh any genetic behavior variation" in development of brain power.

* * *

GENETICISTS, he said, will have to come up with "better data" to support their view that heredity predominates in intelligence.

Dr. Pasamanick is currently involved in his own study of newborn babies and their followup.

His results thus far have shown that babies born to all types of families showed about the same intellectual capacity at 40 weeks.

But when studied at age 3, they began to show differences, depending on the cultural stimulation to which they had been exposed.

Chicago Tribune
Thursday, March 13, 1958

FEARS MENTAL HOSPITALS ARE LOSING GROUND

Need More Help, Skill, and Facilities

Development of better hospitals for aggressive treatment of the mentally ill was predicted yesterday by the superintendent of a state school for the retarded.

But conditions in many existing institutions probably will get worse, predicted Dr. Gale H. Walker, head of the Polk [Pa.] School for the Feeble Minded.

build enough bed space to house all the mental defectives who may need institutional care," he said.

[There are more than 300 names on the waiting list for the mentally retarded children's unit at the Dixon State hospital in Illinois.]

Predicts Some Progress

But Walker did foresee growth of some few existing institutions into what he termed "hospitals in the true sense," admitting patients on a pilot basis, creating new techniques, and associated with medical schools and research facilities.

He was critical of today's institutional care for the mentally retarded.

"If we consider the institution today and compare with what it was in years past, we find that our institutions have not changed radically in structure, in philosophy, or in staffing pattern."

First Meeting of Its Kind

Moreover, within the last 10 or 15 years, he noted, many institutions have been receiving more severely retarded patients than formerly. This is due, he said, both to community facilities caring for

Charleston News
March 11, 1958

Confo On Mental Retardation

SPRINGFIELD — The nation's first regional conference on Mental Retardation will be held today through Thursday at Chicgo's St. Clair Hotel, it has been announced by Dr. Otto L. Bettag, state welfare director.

Sponsored jointly by the Illinois Department of Public Welfare and the U. S. Public Health Service, the conference will explore the problems of mental retardation at national, state and local levels.

Eighty delegates from Indiana, Michigan, Ohio, Wisconsin and the host state, Illinois, will participate. An additional 45 persons, representing community agencies, special education and child welfare services at the national and state level will aslo attend.

"It is the goal of the conference to bring about improved services for mentally retarded persons in the Midwest and other states by providing for an exchange of ideas, problems, concerns and experience," Dr. Bettag explained.

Belleville
News- Democrat
March 10, 1958

Regional Meeting On Retardation

CHICAGO (UP) — Eighty de gates from Illinois and four oth states will arrive here Sunday f the nation's first regional conf ence on mental retardation.

The conference is sponsor jointly by the Illinois Public W fare Department and the U. Public Health Service, with In ana, Michigan, Ohio, Wiscons and Illinois representatives tending.

The conference will end Thur day. Illinois Public Welfare Dire tor Dr. Otto L. Bettag said t meeting will explore the probler of mental retardation at the n tional, state and local levels.

Dr. George S. Stevenson, co sultant to the National Associati for Mental Health, will addre the opening session of the co ference.

Research Links Mental State To Nutrition

By Robert S. Kleckner

More and more research—which already has shown some results—is going into a sturdy of the relationship of nutrition and metabolism to mental retardation.

Dr. Stanley W. Wright, pediatrician at the University of California Medical Center, Los Angeles, outlined some of the work as he addressed the Conference on Mental Retardation at the St. Clair Hotel.

Recent Effort

Dr. Wright said that studies already have indicated that in about 3 per cent of the cases there were biochemical aspects.

Only in the last few years have those concerned with mental deficiency branched into detailed research seeking a pos-

Clinton
Journal-Public
March 10, 1958

Conference On Mental Health Opens In Chicago

Chicago—(UP)— Eighty gates from Illinois and fou er states will arrive here day for the nation's first re conference on mental re tion.

The conference is spo jointly by the Illinois Publi fare Department and the Public Health Service, wit ana, Michigan, Ohio, Wis and Illinois representativ tending.

The conference will end day. Illinois Public Welfa rector Dr. Otto L. Bettag s meeting will explore the lems of mental retardation national, state and local le

Dr. George S. Stevenso sultant to the National A tion for Mental Health, v dress the opening session conference.

CHICAGO SUN-TIMES, THURSDAY, MARCH 13, 1958

Dicts Helpful

He said it had been demonstrated that in some disorders of protein, carbohydrate, fat and hormone metabolism, mental conditions could be affected.

As a result, specific diets have been used to control and improve some of the cases.

Preliminary research has provided evidence, he continued, that biochemistry likely will have a growing importance in prevention and treatment of some mental ailments.

Dr. Gale H. Walker, superintendent of the Polk State School, Polk, Pa., said that on a national average institutions for the mentally retarded were 20 per cent overcrowded, all with long waiting lists.

Issue Of Care

Dr. Walker said "we have permitted the parents and public to convince us we should give a cradle-to-the-grave care to the mental defectives." He expressed the opinion this was unnecessary in many cases in which patients could be improved to where they could be cared for at home with frequent readmissions to the institutions for additional therapy.

Chicago Daily Tribune
Friday, March 14, 1958
Part 1—Page 20 F

WAYS TO AVERT BRAIN DAMAGE IN BABIES TOLD

A psychiatrist asserted yesterday that half of the 60,000 American infants born each year with brain damage could enter the world as normal children if all present medical skills had been focused on the mothers to prevent pre-natal complications and premature birth.

Dr. Benjamin Pasamanick, director of research of the Ohio State university medical school's psychiatric institute, said such an objective would be an "enormous task." For instance, he said, in some areas an intensive educational program would be necessary to convince many would-be mothers that careful periodic pre-natal care was needed.

Dr. Pasamanick was a speaker at closing sessions in the St. Clair hotel of a five state regional conference on mental retardation.